Illinois PKU Press

Spring 2017

2016 Annual Meeting Follow Up

The 2016 year marked a lot of changes for the PKU Organization of Illinois. While some of these changes were more subtle than others, some of the more noticeable ones took place with our annual meeting. Saturday, November 12, 2016 The PKU Organization of Illinois held it's Annual Meeting at the Hilton Oakbrook Hills Conference Center in Oakbrook, Illinois. The theme for the conference was "Looking to the Future".

Dr. Olaf Bodamer

Our Keynote Speaker for the day was Dr. Olaf Bodamer, who is the Park Gerald Chair and Clinical Chief of Genetics, Genomics and Metabolism at Boston Children's Hospital/ Harvard Medical School. Dr. Bodamer presented on "Novel Therapeutic Approaches for Inborn Errors of the Metabolism." Dr. Bodamer touched on curative treatments, such as, gene therapy, bone marrow therapy, liver and stem cell transplantation/therapy. He also spoke about treatments that take the symptomatic approach, such as, Peg-Pal.

Brenda Winiarski , CFL

Another change in the day was our cooking demonstration. This year we had the honor of having the astounded Brenda Winiarski, founder of Cook for Love provide the low protein lunch, along with a hands on demonstration of the foods she prepared. Brenda has been a huge inspiration to the metabolic community, it really was a delight to have her join us.

An additional change we had to this year's program was replacing the breakout session with a panel. The panel consisted of a moderator, an allied disorder adult, a parent of two early childhood PKU boys, a middle school PKU patient and his father, and a father of a young adult PKU patient. The moderator started with questions that had been prepared in advanced and then opened the mic up to audience members. This format really allowed for patients and family members to see and experience the problems and solutions that the PKU and allied disorder patients face at various stages of their journey. We are very thankful to those who were

willing to participate in our panel.

Thank you to everyone who attended and helped make this an event to be remembered!

Inside this Issue

Illinois board members
at the 2016 NPKUA conference

Atlanta, GA
July 5-8, 2018

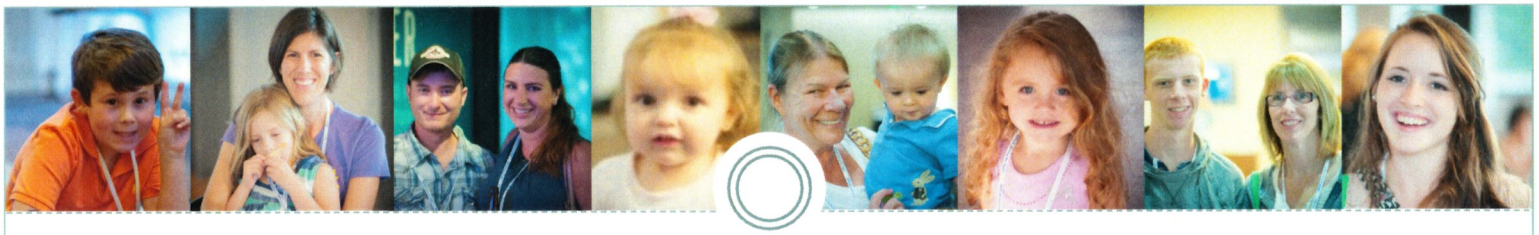
Save the Date for the 5th NPKUA Conference!

Help us find a cure; join the PKU Patient Registry today!

The National PKU Alliance, partnering with the National Organization of Rare Disorders, is excited to announce the successful launch of the PKU Registry in January 2017. This patient centered registry has great potential to accelerate research and improve outcomes for individuals with PKU. Open to all individuals with PKU, or a parent or guardian, the on line Registry uses a survey format to collect information about the natural history of PKU. Surveys cover topics such as phenylalanine levels, PKU diagnosis, genetics, family history, insurance, mood and more. Once entered, participants will have "real time" access to their information as it compares with others in the registry.

PKU Registry enrollment has reached 500 within the first 2 months thanks to the support of PKU groups and industry partners. On line tutorials demonstrating the registration process and survey completion are available on NPKUA's website. Surveys can be completed at your own pace and can be saved and resumed at a later date.

Enrollment in the PKU Patient registry is free and open to any individual with PKU or that individuals' parent or guardian. We hope that you will join the PKU community by registering and completing your surveys. Together we can make a big difference in the future of PKU. Questions about the registry can be directed to Eileen Blakely, RD, PKU Registry Coordinator at Eileen.blakely@npkua.org or by calling 715-493-0074. To enroll or learn more visit https://pku.iamrare.org.



PKU PATIENT REGISTRY

The National PKU Alliance (NPKUA) has created this registry as part of its mission to improve the lives of individuals with PKU and pursue a cure.

The PKU Patient Registry is a patient-driven, natural history study that consists of electronic surveys to collect information about the patient experience and disorder progression. Patients, or their caregivers or guardians, can enter information from anywhere in the world. The data is made anonymous and stored securely in an online portal called a registry. The NPKUA may share the data with individuals or institutions conducting research or clinical trials as approved by the study's governing board that includes scientists, doctors and patient advocates.

Join us to help accelerate research for PKU and find a cure! ***http://pku.iamrare.org***

National PKU Alliance
NPKUA.org

National PKU Alliance

Phone: 715-493-0074
Fax: 715-453-7670
Email: registry@npkua.org

Wine Tasting & Silent Auction Follow up

In October, we had our annual Wine Tasting and Silent Auction. No one could have asked for a better night! The weather was unseasonably warm, and the Cubs and Blackhawks were in town making history as well. This year we changed up our format and introduced a new online bidding feature called Gesture. Gesture allowed people the ability to enjoy the lively atmosphere and complete their bidding from where they sat. We also replaced the party poppers and did a cork pull. This year some of the prizes included Bears Tickets, a Winery Wine Tasting and Tour, Lagunitas Gift Basket, Retro Games Basket and so much more! From this event we were able to raise $3900 dollars towards our scholarship fund!

Family Camp Follow up

This past fall, the PKU Organization had a BLAST as we brought back our annual PKU Family Camp. We kicked off the weekend with PKU "Walking Tacos" as our young chefs learned how to create a flavorful meal on the go. We made new friends around the campfire and ate lots and lots of S'mores. The next morning, we got a jumpstart to our day with a healthy breakfast and headed to the lake. At the fishing derby, we learned everything from how to bait a hook, to how to identify all of the crappie, bluegill, and bass that we reeled in. We were joined by several other day-campers as we worked on arts and crafts, had the chefs in the cafeteria cook us a PKU meal, and then went for a swim in the pool. And what camping trip wouldn't be complete without hot dogs cooked over an open fire? After PKU hot dogs, we learned how to make "orange cakes," consisting of a PKU friendly cake mix baked directly inside a gutted out orange peel! During dessert, we continued to party with karaoke, singing, and dancing. We were pooped by the end of the night. Sunday morning, we woke up, had a tasty PKU breakfast and said our goodbyes until we meet again for another PKU camp next year. We learned so much about how to manage our PKU in a camping/traveling/away-from-home setting, and had a GREAT time meeting new friends and enjoying all of the summer camp activities. This year, we will have camp in Lacon, IL with room for a bigger crowd and many more activities!

Meet Mary Lonski: Illinois Oldest PKU Patient

Walking through the door to the Original Pancake House, I am immediately greeted by a long line of other guests eager to be seated for their mid-morning brunch. Through the pillars of bodies in front of me, I catch a glimpse of the hostess taking names on a waitlist, seating patrons, and delegating table orders to the wait staff. She remains calm and collected in a setting that others may find hectic. The guests wait patiently to be seated, knowing that the hostess is working hard to fill up all the tables quickly, but what they don't know is that this woman is also balancing her own hectic life with PKU. This woman is Mary Lonski. At 59 years old, she is our oldest treated PKU patient in Illinois.

I came to the Original Pancake House to interview Mary about life as a phenylketonuric. We headed back to the break room, and as Mary took her formula out of the fridge, she told me that when she was a child, PKU newborn screening had not been discovered yet. When she was diagnosed at two years old, the doctors told Mary's parents that it was too late and that she would never walk or talk. "If only [those doctors] were here today, they would see me in a different light," she states as she shakes up her Periflex LQ, her current and favorite PKU formula of all time.

Mary has grown up through massive changes within the PKU scientific community. The continued improvements have allowed Mary to conquer many feats. Not only does Mary work two jobs between the Original Pancake House and the Garden Center, but she also volunteers at Christ Hospital distributing magazines, books, and other items to sick patients. If that isn't enough, Mary is also editor in chief for "Runway Newsletter," a monthly edition for the residents at the Garden Center. When asked how she feels about fitting PKU into her busy lifestyle, she smiles and simply states, "it's wonderful."

However, as Mary finishes up her formula, she clarifies that life with PKU has also had its fair share of ups and downs. She recalls being made fun of as a child, but her resilience was no match for these bullies, and their efforts to tear her down only made her stronger. She prevailed and started high school at OW Wilson where she became a cheerleader, president of the student body, and gained the skills that shaped her into the independent woman she is today.

Mary tosses out her empty formula carton and heads back to the hostess desk. I follow quickly behind her and couldn't help but ask what advice she has for the younger PKU generation. Without hesitation, Mary told me "Don't let PKU stop you. If you do, you will regret it. I didn't, and look at me now." I was completely awestruck by the strides that Mary has made despite the lack of treatment available as a child and all of the barriers she has overcome. As I drove home, I was overwhelmed with the feeling of admiration for this remarkable woman. I am so honored to be able to share my experience about our PKU Special Person of the Month, Miss Mary Lonski.

Mary Lonski is also one of PKU organizations amazing board members!

Improving life with PKU: How GMP came to be...

On July 9, 1992 Lynn and I had our second child, Cameron Lake Paolella. He was a healthy 8 pounds 12 ounces (3.9 Kilos), and very engaged with his surroundings when not fast asleep. Like any parents, we were elated with this chubby infant boy with a striking mane of black hair. It was such a remarkable feature – thick and standing at attention – normally complacent nurses came by to see "Don King" -- the baby with hair that looked like the famous boxing promoter!

Only a few days after bringing Cameron home, we learned of another remarkable but hidden feature of our new son, *phenylketonuria*. Lynn got the call that forever changed the course of our lives.

Like many of you, we didn't know what to expect. Our confirmatory diagnostic tests entered Lynn and I into the world of P K U. Life has not been the same since. In retrospect, we are better for it, and thankful to be a part of this supportive community. **What follows is the story of how GMP came to be . . . an alternative protein source for PKU.**

Fortunately, Cameron's diagnosis came in the first week of life and he began the low protein diet that many readers here know so well. Lynn, with an instinct for nurturing and feeding our new best friend, faced most of the daily challenges. It is with Lynn that this search for better PKU food and formula begins.

During the first 6-8 years we struggled with every emotion -- but life got easier as we learned how to manage the diet. In 1997, we were well prepared to welcome our daughter Brooke when she received a classical PKU (R408W/R261Q) diagnosis – thankfully sharing the same alleles as her brother. With the paucity of choices available in the 1990's, food and formula were not very appealing to our son. He was constantly hungry. It became our family's mission to learn about every option for PKU food and formula. Never satisfied, we engaged both commercial food scientists and university researchers in our mission.

While searching to produce better homemade bread, Lynn communicated regularly with Virginia Schuett MS RD (editor of the National PKU News and author of the Low Protein food List) and Sally Gleason MS, RD. Sally had the insight to work closely with the Center for Dairy Research in Wisconsin. One of their research scientists, Dr. Mark Etzel had patented a process for extracting a dairy whey peptide from the cheese making process -- kappa casein glycomacropeptide -- now often abbreviated just GMP. GMP is a unique 64 amino acid small protein (peptide) that contains not a single molecule of Phenylalanine, Tryptophan or Tyrosine - the aromatic amino acids. She believed it could play an important role as a source of protein for PKU.

"It became our family's mission to learn about every option for PKU food and formula."

In 2000, the team of Lynn, Sally, and Virginia had a small supply of this product from Dr. Etzel's lab. Each of them explored the use of GMP to improve the browning of low phenylalanine (PHE) bread. From 2000- 2002 the team experimented with a variety of food applications -- with mixed results. Overall, they were encouraged.

By 2002 Cambrooke Foods had been operating for 2 years and developed more than a dozen low protein food items distributed in the US and Canada. Sally was determined to see Dr. Etzel's GMP get put to practical use and called me to lead a "task force" for industry and academia to explore its potential. Sally Gleason enlisted an expert research doctor from the nutritional science department to investigate the safety and efficacy of using GMP to treat PKU mice. What could we learn about the physiology of a GMP diet when compared with the conventional amino acid diet for PKU? Dr. Denise Ney raised several million dollars from both the NIH and FDA to answer this question. She needed an animal model to compare GMP to an amino acid diet when fed from infancy to adulthood. Dr. Ney collaborated with Drs. Woo and Harding to arrive at the most appropriate clinical model for this study. (We are indebted to a global network of scientists who share their lifetime of learning to advance our knowledge) They focused on this little mouse, called the ***PAH enu-2,*** as an ideal candidate to test such a diet. Before beginning the study, the team bred a small colony of 'mice cousins' in the hundreds with a nearly identical genetic background (PKU mutation). Such "models" are essential to minimize variation in the study design. After 2 years, UW Madison had their mice and the study began in 2004.

There are several papers published from the data collected during these pre-clinical studies, a summary of which is beyond the scope of this article. What was eye opening for Lynn and me were the physiologic improvements in both the PKU and 'wild-type' (normal) mice when fed GMP from birth to adulthood. To my surprise, even the healthy mice, when fed AA diet, had consistently poor health (inflammation, weaker bones, enlarged kidneys and spleen). In contrast, the PKU and wild type mice thrived on the GMP diet. While we know mice are not humans, we also know that nature is very conservative -- the biochemistry of phenylalanine metabolism (PHE --> TYR) is very similar in all mammals. These results had us committed to further testing to see if it could help our children's lifelong health.

Over the next few years, the research team at UW Madison conducted an in-hospital clinical trial of 11 PKU patients, an environment that allowed their diets to be carefully controlled. Each of the subjects served as their own "controls" in a classic "cross-over" design study. From the published data, we learned that GMP was not just a better tasting source of protein for PKU -- but nearly all of the patients improved on 4 critical biomarkers in just a few days of GMP diet! (A subsequent 4- year study, published in 2016 with 30 PKU patients, confirmed these results.)

In 2008, our little Cambrooke Foods had more than 120 low protein foods, a 3,000 square meter processing facility and a ready to drink amino acid product line for PKU and MSUD. We were determined to find a supplier to make a commercial grade GMP to include in a new PKU formula. While there is plenty of whey in America, the small market size, technical sophistication, and investment needed to purify the background whey from the GMP, made it very difficult to convince a commercial dairy to manufacture this product just for PKU.

Solverson, Patrick, Sangita G. Murali, Suzanne J. Litscher, Robert D. Blank, and Denise M. Ney. "Low Bone Strength Is a Manifestation of Phenylketonuria in Mice and Is Attenuated by a Glycomacropeptide Diet." *PLoS ONE* 7.9 (2012): n. pag. Print.

Calcar1234, Sandra C Van, Erin L. MacLeod1234, Sally T. Gleason1234, Mark R. Etzel1234, Murray K. Clayton1234, and Jon A Wolff1234 And. "Sandra C Van Calcar." *The American Journal of Clinical Nutrition*. N.p., 01 Apr. 2009. Web. 02 Mar. 2017.

Ney, D. M., B. M. Stroup, M. K. Clayton, S. G. Murali, G. M. Rice, F. Rohr, and H. L. Levy. "Glycomacropeptide for Nutritional Management of Phenylketonuria: A Randomized, Controlled, Crossover Trial." *American Journal of Clinical Nutrition* 104.2 (2016): 334-45

In the spring of 2008, I had the good fortune to meet with the CEO of Arla Food Ingredients in Denmark. At our first meeting, Henrick Andersen shook my hand and said, "I've been waiting 18 years to meet you!". Henrick knew something about PKU and knew GMP could be a source of low phe protein for us PKU families. We set to work planning our collaboration. Cambrooke would need many millions of dollars for development (which we didn't have) and Arla would need to build a commercial plant to manufacture this special ingredient for the ~60,000 PKU people in the world who could benefit. (As a side note, Phyllis Acosta, PhD of Ross/ Abbott Nutrition, and inventor of Phenex®, later told me she had been interested in GMP as protein source for PKU, "but could never get a source 'pure enough' for a commercial production." Lynn and I would risk everything on the evidence that this intact natural protein would benefit all patients with PKU. We began our journey to raise tens of millions of dollars, expand our manufacturing facility, and bring GMP to the global PKU market began in 2009.

GMP alone is not an ideal protein. Protein quality is the result of a complete range of *essential* amino acids (those not made by the human body) in the right proportions. GMP, as mentioned earlier, is devoid of phenylalanine, tyrosine, and tryptophan and must be supplemented with five "limiting" amino acids. In addition GMP contains high levels of Threonine and other large neutral amino acids (LNAAs) bound in the peptide. (There is evidence that high LNAA concentration can reduce brain phenylalanine by blocking LAT-1 transport) To determine the best proportion of supplemental amino acids to balance the GMP protein, the research and development team examined PKU patient serum amino acid levels, gut microbiota, and potential renal-acid load (PRAL) , among other factors, to determine the optimal formulation for this new protein substitute. The resulting formulation is Cambrooke's patented Glytactin formulation. We have developed and refined this formulation for the past 8 years.

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We are proud to say that our little company Cambrooke Therapeutics, in addition to our range of low protein foods, has more than 18 Glytactin products for PKU and 4 products for Tyrosinemia now available. More than 1000 patients worldwide (including Cameron and Brooke) use our Bettermilk product, available in the US since 2009. We now learn from many what it is like to live with PKU.

We know challenges continue for individuals and families with PKU. Although the dietary options have improved greatly since Cameron was born, it is difficult at every stage of life to maintain targeted serum phe

levels for nearly all classical PKU teens and adults. Many symptoms of transient elevated 'phe' levels plague our children and others with PKU. There are promising new pharmaceutical therapies being studied. Indeed our family has direct experience with 2 of these. We hope to see a safe and effective alternative to this highly restrictive diet in the near future. Until one or more of these alternatives are available, maintaining a low phenylalanine diet is both safe and effective management of PKU.

Stay healthy today for a better tomorrow!

David Paolella
Founder, Director
Cambrooke Therapeutics

Dear Phebea,

Transitioning to High School

Dear Phebea,

My daughter is starting high school in the Fall. How can I help her take ownership of her PKU management?

Sincerely,
Micromanaging Mom

Dear *MM*

Remember when you learned to ride a bike? Your parent or older sibling held on and ran beside you to help you find your balance. Eventually they had to let go and watch you pedal away on your own. What a great feeling—for all involved!

Similarly, the teen years are fraught with trepidation as well as exhilaration—for both parents and kids.

As parents, we know and fully accept the importance of proper PKU management; the challenge can be getting a teenager fully on board. And when your teenager doesn't feel or notice any difference when phe levels are high, things are even more difficult.

By the age of 13 or 14, areas of self-monitoring include formula preparation and consumption, meal planning, and phe tracking (Trahms). Here are some tips to help your teen take charge.

1. **Formula intake**. As you transition the day-to-day management of formula preparation, talk to your teenager about his or her PKU routine. Are they happy with their current formula regimen? Maybe it's time to sample new products that are more convenient to use during a busy school day. Remind them that formula intake evenly spread throughout the day will help them feel and do their best.

   Tip: Establish a consistent formula prep routine for the school week. Is it the night before or the morning of? Keep track of the days your student accomplishes this vs how many days you do it. Provide positive feedback—and, as hard it as it may be, try not to nag!

2. **Meal planning**: Adolescents often skip meals or eat at odd hours, which can lead to snacking in response to hunger rather than having a meal. Have healthy PKU snacks to choose from on busy school days. Teenagers who help prepare appropriate nutritious snacks/meals are generally healthier eaters, so get them involved!

   Tip: Set aside a day to plan meals for the week together. Work together on chopping go-to fruits and veggies for the week. Include portions to snack on and some to be added to meals, such as LP pasta or soups. Fill fun containers in the fridge for easy access. Set the example by providing these for your teen. Gradually hand over the tasks as time allows.

3. **Phe tracking.** Help your teen take charge of their day-to-day phe management. How many days of the week was goal phe intake maintained? Formula intake maintained? What were the obstacles?

   Tip: Track phe/protein using an app or website such as accu-go, mypkudiet, myfitnesspal or howmuchphe.org. With your permission, have your daughter or son download and email the diet records to their dietitian who can provide helpful (non-parental!) feedback.

Remember that first two-wheeler? You might have gotten off to a shaky start but in no time you were flying along under your own power. As hard as it may be, parents eventually must let go. Remember that the teen years are a work in progress--give your child greater independence as well as lots of TLC. Before you know it, your teen will be moving out—off to college or their next great adventure. The good habits you have already established along with a lot of Patience, Persistence and Planning will pay off!

Sincerely,
Phebea

Further Resources:
http://ellynsatterinstitute.org/htf/12to17years.php
http://ellynsatterinstitute.org/hte/everybodydoesbetterwithfamilymeals.php#sthash.E4PYFukM.dpuf
http://depts.washington.edu/pku/management/curriculum/teen/independence.html [Cristine M. Trahms Program for Phenylketonuria]

Andrew Craig Scholarship Winners

See what our scholarship winners have been up to and how they handle having PKU!

Melissa Bernzen

I was born with PKU and the one thing I love most about having PKU is how it has guided me through life rather than taken control of it. As a child, I thought of my diet as an annoyance that made me an outcast, but my parents would always go the extra mile to make me feel included. I was always self-conscious of drinking my formula in public especially at school, but I learned at a young age that the typical response to finding out about my disorder was more curiosity than judgment.

Growing up, I moved to many different schools having to make new friends, and meeting new people meant having to explain my diet again. As I got older talking about my diet became less of a chore and I noticed that I enjoyed educating people about this rare disorder. My passion and confidence for educating others about PKU can mostly be credited to my parents because they were able to provide me with the knowledge and independence I needed at a young age to take care of myself.

Currently, I am a degree candidate in the Master of Science in Nutrition and Dietetics at Eastern Illinois University. I elected to write a master's thesis, which is about the financial burdens associated with managing PKU as an adult. I have submitted a systematic review evaluating the financial burdens of treating PKU for all age groups, for possible publication. By expanding on the current literature as well as my own knowledge base, my goal is to educate and raise awareness to the public and legislatures that medical food and formula needs to be better covered through insurance and/or state programs in order to provide treatment for both children and adults.

Having PKU has given me firsthand experiences and personal insight to the challenges people with metabolic disorders face every day. With my personal insight on maintaining this life-long diet I hope to specialize as a metabolic dietitian and serve as an advocate for this community through research and lobbying.

Allyson Ruckman

PKU has been a big part of my life, but I would say that I have not let it run my life. My first semester of living in a dorm was very challenging, but I have learned how to make it work. At my request (and a letter from my amazing dietitian) I was able to be placed on a floor with a small kitchen. My roommate and a few other girls on my floor are enjoying my culinary skills and lots of stir fry vegetables. I love cooking and trying new recipes when I am home on the weekends.

When I was younger I usually didn't share with others that I had PKU. Now that I have gotten older I have learned to embrace who I am and make the best of it. Now it seems that being vegan is the "in" thing. Who knew I was so cool all these years? It definitely has helped with finding food in restaurants and in stores. I was so excited to see vegetarian sushi on the menu at my favorite restaurant. Only a person with PKU would know how exciting that is!

I am in my freshman year at Western Illinois University in Macomb majoring in Agriculture (Animals Sciences). Anyone who knows me knows my love of animals (especially Dr. Hoganson). I appreciate being awarded the PKU Scholarship. The money was put to good use on tuition and books.

Alex Seidler

PKU motivated me to fight my hardest for everything I wanted in life. I came from a family of 16 kids and I was the last one to be diagnosed with PKU after three other siblings. After I was taken away due to high blood levels I was adopted on my fourth birthday and never looked back.

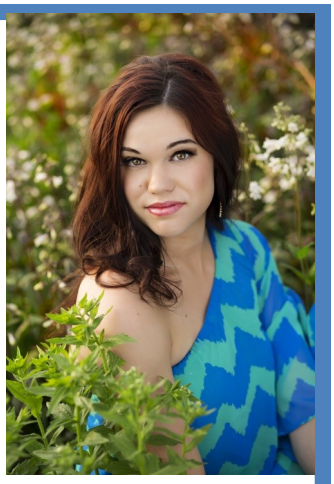
I've been fortunate to have supportive family members and friends. While I struggled in school up through high school I always kept a positive attitude and mindset that I'd make something of myself. Throughout my life I've learned to always look forward because the past can't change but the future can. I always felt I had something to prove which is why I constantly think about my future. I believe we all have a story to tell and challenges that we've faced.

Coming to college has had a profound impact on me. I knew living with my family, taking care of my PKU would be easy but the best sign of maturity to me is how I could handle it on my own. I not only became more independent but I took advantage of all the opportunities offered to me. My dining hall cooks were generous enough to prepare my medical foods for me.

College has given me the opportunity to demonstrate my true potential. I got involved with eight clubs my freshman year and remain in four of them. Most of the clubs correlated to my career ambitions of being a storyteller. I love hearing other people's stories and then I share mine so we can inspire each other. One of my goals in life is to inspire others whether that is telling my life story, fiction stories, or advocating.

I graduate from Eastern Illinois University in May with a Bachelor's Degree in Mass Communication. I have several career ambitions but my first will be public relations. However, I've applied to the Peace Corps, which is my first choice, so I can do something meaningful before I jump into my career. But I'm proud to say I haven't put all my eggs in one basket. I've applied to the Washington Media Institute and Americorps which I've heard positive feedback from both. I never thought I'd have all these opportunities and I couldn't be more excited for what my future holds for me.

Alicia Kimbrell



I was fortunate enough to be awarded the 2016 Andrew Craig Scholarship. I have PKU, which has really helped to shape me into who I am today. I have learned many things from my journey with PKU, but there are a few that stick out more than others. One is that I have learned that no one choses the way that they are. Having PKU has helped me to be more accepting of everyone, no matter who they are or what they are dealing with. Another thing that I have learned with PKU from a young age is how to pay very attention to my diet and what I eat everyday. This has forced me to think about nutrition and what I put in my body. I am thankful that I have learned to be conscious of what I eat because it has helped me in adjusting to college and living on my own.

I am currently a junior at Indiana University-Bloomington. I am studying Informatics and Computing, with a focus in Graphic Design. I hope to after college get a graphic design job, where I can create a career around creativity and design. In college, I have gotten involved in many things, including joining a sorority, and a being on a committee for the Indiana University Dance Marathon. I have lived in the dorms and in my sorority, so I have had to learn how to work with the cooks in the dining hall, and the chefs at my sorority to ensure that I have enough low-protein foods available for me to eat. It is definitely harder in college to follow the PKU diet, but with the help of the chefs and my parents I have been able to still get the foods that I need. Although I sometimes have to go out of my way to deal with my diet, I am so lucky that PKU is something that can be treated, and that I have had the support of my parents. They bring me my formula and foods that I can eat to school every month, and I wouldn't be able to be doing the things that I am without them.

I am so thankful to have received this scholarship! It has helped me to pay for my tuition and my textbooks. I am very excited to continue living healthily with PKU while heading into my final year of school in 2017.

Are you in or entering college?

Are you looking for scholarships?

Do you have PKU or an Allied Disorder?

You may be eligible!

Visit: PKUIL.org > Resources > Scholarship forms

Deadline August 31, 2017

BLACKBERRY FARMS

100 S. Barnes Road - Aurora, IL

Registration includes Admission and Lunch!

$32 per adult and $24 per child (before 4/29)

$40 per adult and $30 per child (after 4/29)

Hayrides - Carousel - Petting Zoo - Train Rides & more

FREE event brought to you by the PKU Organization of Illinois

Parent Cafe

Grounds for Hope Cafe (inside Trinity)
2701 Maple Avenue, Lisle IL 60532

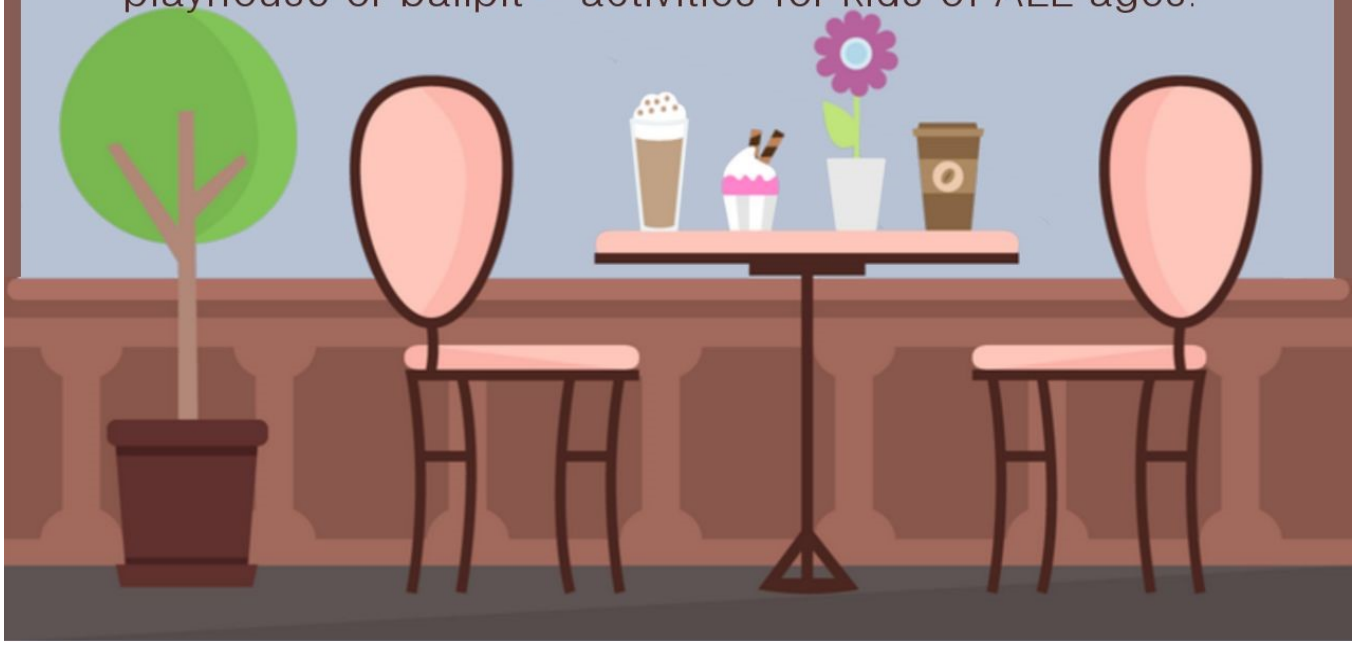
June 10, 2017
9:30–11:30 am

We're thrilled to bring you a FREE event to network with other PKU families

Bring your kids, and stop in for a light brunch (PKU foods will be provided)!

Meet other PKU Parents, Adults with PKU and low-protein vendors

Exchange tips and tricks while the kids play in the playhouse or ballpit – activities for kids of ALL ages!



A FLAVORFUL FUNDRAISING EVENT

GO MONGO FOR PKU!

ORIGINAL bd's Mongolian Grill SINCE 1992

Thursday, June 15, 2017
5:00 - 9:00pm

BD's Mongolian BBQ (Downtown Naperville)
221 S. Washington Street, Naperville IL

Join us for a PKU-Friendly Stir Fry Meal!
Help support and raise awareness for PKU. Kitchen Scales and stir fry recipes will be available for PKU diners!

Upon Arrival, simply mention you are with PKU Organization of Illinois and BD's will donate $3 per person in your party to PKU, plus, we'll receive 80% of tips at the Grilling Station!

Everyone is welcome – NO RSVP NEEDED – Please Share this Flyer!

PROMIN

Promin Are Pleased To Launch Our New U.S Website!!

You can find all your favourite Promin products
including Promin Burger and Sausage mixes
plus some new additions to the range at

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EASY PKU Microtabs

PKU Easy Microtabs:

For ages 3 and up, these are tiny tablets that are swallowed and replace standard formula.

PKU Easy Microtabs contain a slow release coating that helps prevents amino acid breath, while masking the unpleasant taste often associated with PKU formula.

These unique microtabs are usually taken with water, juice, or Gatorade, but our younger clients have been known to prefer with applesauce or jam.

"I love my microtabs. They make life so much easier than the past 27 years have been with liquid formula. Thank you."
~Callie M.

"I know there are other pills out there for PKU but they were too BIG (and too many) to make feasible for my son. I cannot thank you enough...my son has finally been taking his entire formula for a month now. Your PKU Easy Microtabs are a Godsend."
~Ann M.

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PKU Shake & Go:

A complete formula with 15g phenylalanine-free protein for ages 3 and up.

PKU Easy Shake & Go is a "Just-In-Time" orange flavored powder in a pre-measured bottle.

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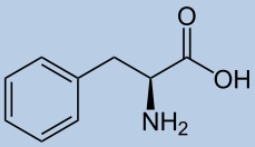
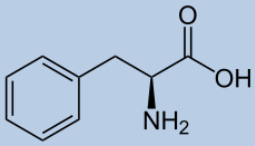
PKU Shake & Go is convenient and makes traveling a breeze.

"Finally a convenient formula that actually tastes good. Thank you!"
~Mark B.

Meet our pHEnomenal Board





My name is Danae' Bartke. This is my fourth year on the board, and my second year as president. I have been the Editor in Chief of the PKU Press the entire time I've been on the board. I have had my hand in almost ever aspect of the various events. I love helping plan and implement each activity! My goal for my last year on the board is to make sure everything is organized and create a smooth transition for our next president and round of board members in 2018!

My name is Grant Smith. This is my 5th year on the board and first year as Vice President. I have a 5 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.

I'm Ami Vanderhoof, Treasurer of PKU Organization of IL and mom to a very happy (and adorable!) 3 year old, Logan, who has PKU. 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. My primary goals while serving the board include providing fun and positive experiences for PKU families, encouragement and support to new parents, and finding new and exciting ways to raise funds for the organization we are all passionate about.

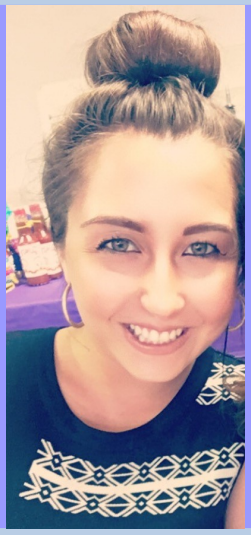
My name is Kim Kowalczyk and I am currently a Physician Assistant in Emergency Medicine. Growing up, I have always enjoyed attending PKU conferences and functions with my older sister who has PKU. Listening to the doctors and researchers speak about the latest advances in PKU science and medicine have inspired me continue my involvement in this field. Last year, I joined the board as the Illinois Representative for the NPKUA, and became involved in important matters regarding PKU legislation and research. Now, I have taken on an additional role as Secretary of the PKU organization of Illinois, and will also be planning the PKU Family Camp that will take place in the early Fall. I am honored 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.

My name is Andrea Hall and I've been on the board for 4 years. The PKU Organization of IL is very important to our family because our daughter was diagnosed with PKU 6 years ago. We were introduced to the PKU Org as a source of support and have been grateful ever since. Joining the board is our way to help other families. My goal this year is to help raise as much funds for the organization and awareness and education for the community.

My name is Matthew Bartke and this is my third year on the board. I am the website administrator. My goal is to make sure things are up-to-date and easily accessible through the website.

For the most up to date event listings, please make sure you are checking the website!

Hello, my name is Elena Caro. 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.



My name is Sean Haney and this will be my first year serving on the board. I have PKU and recently graduated from the University of Illinois at Urbana-Champaign in May 2016. I have been looking for a way to become more involved with the PKU community for some time now and could think of no better way than to join this organization. My goals for this year include connecting with and providing social support for those individuals and family members affected by PKU and other allied disorders as well as contributing however else possible

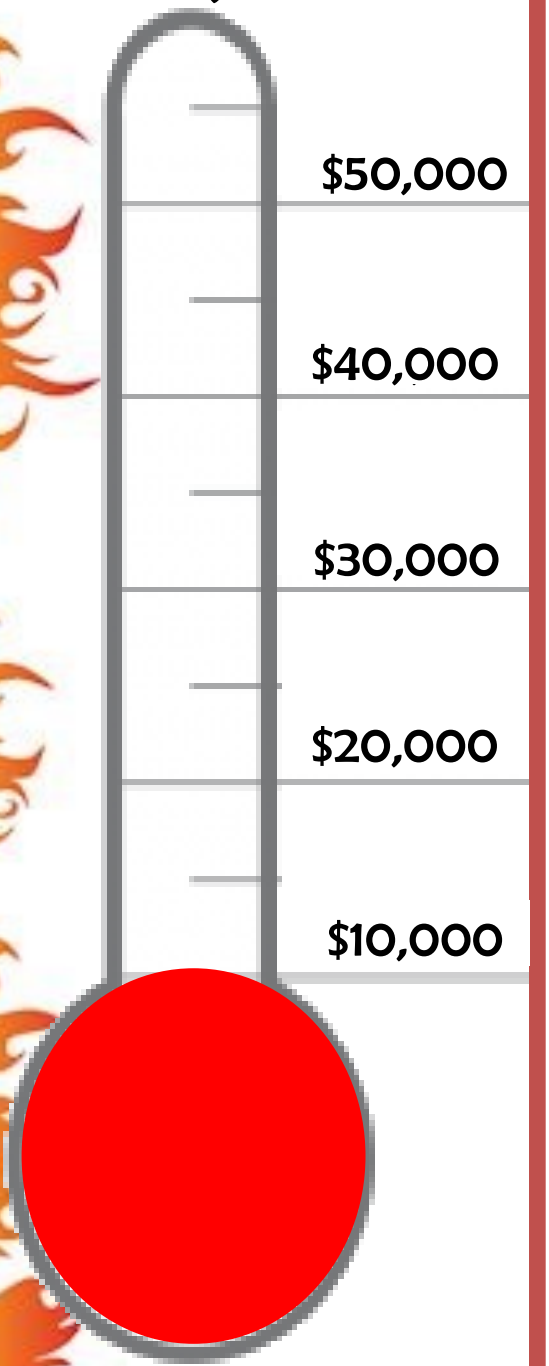
Soo Shim MS, MBA and LCSW I have been in the Social Work field with twenty-six years of experience working in medical Social Work. I am currently employed at the Ann and Robert H. Lurie Genetics Division. I have spent my career working in the medical field and as a social worker. I love supporting and 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 graduate Masters 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

Shannon O'Brien is one of three metabolic dietitians at the University of Illinois at Chicago. She sees patients in Chicago and at satellite clinics in Oak Lawn, Naperville, and Springfield. She has been working at the University for 3 years and this is her first year on the PKU Board. She received her Master's in Nutrition from UIC in 2012 and loves working in metabolics. When not at work, Shannon is often on the sidelines of her four children's sporting events or trying to get that nutritious dinner on the table for her family!

My name is Katie Patiewicz and it is my second year on the board! I'm a stay at home mom/full-time college student at CLC. My two kids have PKU. Drew is 7, Hailey is 6. I'm back in school to pursue a degree in history, to teach high school or middle school history. I'm a veteran of the US Army and I love history, science and reading. My kids are excelling, Drew loves video games, math, baseball, football, and football; Hailey loves princesses, shopkins, art, and gymnastics. They are my world and my hope is to raise awareness for PKU and also to raise funds, not only for research, but also for us to gather as a community for more events.

Help Spike the PHEver for a Cure

$60,000



How will it be spent?

$2,000 CookforLove.org
$3,000 How Much PHE
$7,000 Clinics
$8,000 Scholarships
$10,000 NPKUA Research Fund
$30,00 Operating Cost
(Operating cost includes the price of events)

Donation Levels

Hazel Vespa: $100

Barbara Burton: $250

Brenda Winiarski
(Cook for Love founder)
$500

Virginia Schuett:
$1,000

Pearl S Buck (Author of
"the Child who never Grew")
$2,500

Dr. Robert Gutherie
$5,000

Dr. Asborn Folling
(Founder of PKU)
$10,000

Many of you met Brenda at our annual meeting, and some of you knew her before hand through her website and Facebook group, Cookforlove.org. Brenda has been the Julia Child of the PKU community. From her good to the last bite Kentucky Fried Cauliflower to her more scrumptious pumpkin scones, her recipes have rocked the world's of the children and adults who have tried them. Here are a few more to try out—to find more delectable eats, please visit Cookforlove.org!

Veggie Burger #2

Author: Brenda Winiarski
Prep time: 25 mins Cook time: 6 mins Total time: 31 mins
Yield: 5

I have to confess, I was never 100% satisfied with my old veggie burger recipe. The texture just was not quite right. Then Konjac came into my life. This is the miracle ingredient I have been looking for when it comes to binding savory foods. These are seriously the best veggie burgers (high or low) that I have ever had. I do think that with a bit of work, I can bump down the phe a bit but since it works with Molly's diet, I was impatient and wanted to share right away. Enjoy on a low protein bun with ketchup, thousand island dressing or chipotle mayo. Top with pickles, red onion and lettuce.

Ingredients

- 1 tablespoon brown sugar
- 34 gm ketchup (2 tablespoons) ketchup [20 mg]
- Tabasco to taste, optional
- 5 gm (1 teaspoon) yellow mustard [8 mg]
- 5 gm (1 teaspoon) Worcestershire sauce [5 mg]
- 2 tablespoons olive oil
- 150 gm (about 8) cremini or (2) Portobello mushrooms, finely diced [116 mg]
- 60 gm (1/2 small) italian eggplant, peeled and finely diced [26 mg]
- 75 gm (1/4) onion, finely diced [19 gm]
- 5 gm (1 large clove) garlic, minced [8 mg]
- ½ teaspoon chili powder, optional [6 mg]
- ½ teaspoon salt
- dash Tabasco, if desired
- 1 tablespoon butter [12 mg]
- 150 gm cooked short grain brown rice [177 mg]
- 5 gm parsley [8 mg]
- 50 gm (1 slice) of CFL bread lightly toasted [21 mg]
- 1 teaspoon konjac

Instructions

1. Combine the brown sugar, ketchup, mustard and Worcestershire sauce in a small bowl and set aside.
2. In a large skillet, heat one tablespoon of olive oil over medium high heat. Add the mushrooms and cook until lightly browned, about 5 to 6 minutes. Add remaining oil and eggplant and onion. Cook an additional 5 minutes, sitting occasionally. Add the garlic, salt and chili powder and cook for one minute. The vegetable mix should be fairly dry. Add ½ of the ketchup mixture to the vegetables and and simmer an additional five minutes. Add the butter. Add Tabasco if desired. Remove from heat.
3. In the bowl of a food processor process the lightly toasted slice of low protein bread until it is in crumbs. Add to a medium sized bowl and set aside. Add the brown rice and parsley to the food processor and process until the rice is a little sticky, about 30 seconds. Add the cooked vegetable mix to the rice and pulse 4 to 6 times to combine.
4. Place the veggie and rice mixture into the bowl with the bread crumbs. Add the konjac to the remaining ketchup mixture. It will thicken considerably. Add to the vegetable mixture. Stir to combine thoroughly.
5. Form into five 80 gm patties and put in the fridge for two hours. Freeze what you are not using in the next three days.
6. Heat olive oil in a skillet. Cook burger for about three minutes, flip and cook another three minutes. Serve on low protein bun with desired toppings (chipotle mayo, red onion, lettuce, pickles, avocado, etc)

Nutrition Information

Serving size: 1 burger (80 gm) Phe Per Serving: 84 mg Mg phe/ Gm food: 1.05 mg/gm Calories Per Serving: 113 kcal Phe Per Recipe: 420 mg Calories Per Recipe: 566 kcal Protein Per Serving: 1.92 gm

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