



## Illinois PKU Press Spring 2016

# 2016 Annual Meeting Follow Up

Saturday, November 7, 2015 the PKU Organization of Illinois held its Annual Meeting at the Holiday Inn, Skokie. The theme was "Milestones in PKU & the Allied Disorder Community." The meeting was very well attended, with approximately 120 people present.

This year's guest speaker was Dr. Kendra Bjoraker founder of 3:1 Neuropsychology Consultants, PLLC. Dr. Bjoraker presented on how Phenylalanine and other amino acid disorders affects the

brain at the various stages of development. She spoke about the factors that affect functional outcomes, such as attention, processing speed, memory, and executive function.



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## A Note to all PKU PRESS Subscribers—

After much consideration by the board,, we will be changing the format for the print publication of the PKU Press. The PKU Press is very costly to print and mail and we as a board feel that the financial resources that are spent on this could be better allocated in other areas, such as donating to research for a cure, or clinic support.

Starting 2017, the print mailed edition will be at a small nominal annual fee. This fee has not yet been determined, and will cover both Fall and Spring editions of the PKU Press. The Fall 2016 PKU Press will have the form to complete, if you wish to still continue receiving it by mail from 2017 onwards. If you have any questions about this decision, or about receiving it in the future, please email or call the board.

The 2016 PKU Organization of Illinois Board

# From Adoption to the Crown: Miss Illinois International 2015, Ruthie Jaeger



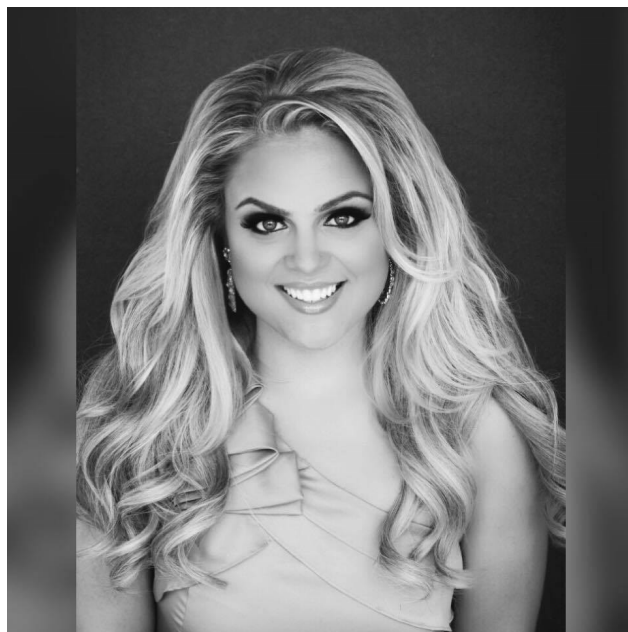
Three weeks after I was born, Social Services took me away from my biological parents after they refused to give the proper treatment for my PKU. After four years, my two brothers and I were adopted by my foster parents into their family of three children which would make for a total of six. It was a blessing in disguise because my foster parents, who I now consider my parents, learned all about PKU so they can raise my brothers and I with the proper treatment.

I've had some struggles growing up trying to understand why I couldn't have just some of the pizza at birthday parties or some cake and ice cream. At times I would even cry asking my mother why did I have to have PKU. My mother gave me the best answer that has always stayed with me. She told me that everything happens for a reason and that if me or my brothers didn't have PKU, then we wouldn't have crossed paths in life because at the time my parents only took in children who needed help. I wouldn't be the woman I am today if it weren't for having PKU. So I took it to my advantage. Instead of getting upset about it, I took it as a way to share my whole story about PKU and adoption and how they both were the best things that have happened to me. I still have rough moments, but it is always expected for anyone with this disorder. I am learning everyday something new about my genetic disorder. I still get frustrated at times when I have to drink my formula or when I go to a restaurant and there aren't many options to eat, but I just remind myself what my mom has always said. This is something that I have spoken about throughout my year as Miss Illinois International. Everything happens for a reason. Instead of being negative about anything you may be dealing with, learn to embrace it. Having PKU is part of my story with

adoption because without having PKU, then I wouldn't be here speaking to people, sharing my story, educating to spread awareness about PKU. It is something that I have been so grateful that I have gotten the opportunity to do.



As a Miss Illinois titleholder with PKU, it can be pretty challenging at times when it comes to managing my PKU diet, but I have to say that I have become a pro at it! I am always on the go when it comes to appearances, photo shoots, or speaking engagements so preparing my PKU needs in advance is a must! The night before I always measure out my formula in separate containers so I can put it right in a shaker cup when I need it. I also always have low protein snacks with me such as carrots sticks, my low protein Light Tapioca Bread, and even So Delicious Yogurts. I like to keep track of how much protein I eat throughout the day by keeping it in my phone. I get so caught up with everything that sometimes it can be challenging to remember so I just look back on it!







As a newborn, I was put into foster care after my biological parents refused to treat me and my two brother's PKU. I really had to create a schedule for myself when it came to managing my PKU. As a title holder I am always on the go for appearances or driving out of town for photoshoots so preparing in advance was the key for me. I would pack my formula up in little containers so it was easy to pour into a shaker cup. When it comes to my food, I always portion size everything so I would know how much protein I am eating.

In the end, remember it is all about how you feel about yourself. Do what makes you feel great because when you do that, it all falls into place!

Miss Illinois International 2015,  
Ruthie Jager

Having PKU, it can be difficult to stay physically fit. I used to have an issue with this growing up because I was always hungry so I was always eating. The thing that works best for me and the best advice I have is to portion size. Anything you eat needs to be in moderation and you should be eating 5-6 times a day. This will increase your metabolism and when you eat every 2-3 hours, you won't be as hungry. I like to limit my carb intake to only having them in the mornings and during lunch. This will help it burn off by the end of the day. When I choose low protein foods, I try to go the healthiest route. There is a Tapioca bread made by Energy Foods and they have a regular kind and light kind which has less sodium and fewer calories. That is the one I always go with and it tastes great! Aside from eating well, I drink a lot of water throughout the day. I always have a bottle of water on me which helps me with my water intake. Finally, I workout 4-5 days a week. To see any type of results, it is very important to do some type of workout. After my workout, I always drink my formula. It's great for the muscles just like when people take their protein drinks after workouts. Our formula is our protein.





# Recipes from the Board



## Apple Cheddar Quesadillas

By Andrea Hall

### Ingredients:

1 Tortilla (Cambrooke Foods Tortilla - 4mg for whole tortilla)  
1 Slice Cheddar Cheese (CBF Cheese - 1 slice = 20mg)  
182g Granny Smith Apple (or any tart apple) - sliced thin (11mg)  
Dijon Mustard, French Dressing, or a Chipotle Sauce

### Directions:

Preheat oven to 325 degrees. Place tortilla on a cookie sheet and spread on your sauce of choice (Dijon mustard, French dressing, or chipotle sauce) on the entire tortilla. Then on one half of the tortilla place your sliced cheese. You will need to break up your sliced cheese to fit on the half and it will overlap. Then place as many thinly sliced apples, as you would like, on top of the cheese. Then fold the tortilla over (the side that has nothing on it should fold over on the top). Put the quesadilla in the oven for 5-8 minutes, or until cheese is melted. Then serve and enjoy!

We have made these as a regular dinner in our house. We make the low protein version for our daughter and then use regular Sharp Cheddar Cheese and a regular tortilla for the non-low protein family members. We serve this with a salad and a vegetable and make it a great, all around, family meal.



Makes 1 serving—35 mg PHE  
Does not include condiments in total.

## No Chicken Salad Wrap

Makes 8—1/4 cup servings (23 mg PHE per serving without lettuce)

### Ingredients:

20 oz Canned Jackfruit in Brine, rinsed thoroughly (92 PHE)  
2 cups Vegetable Stock (365 Everyday Value—10 mg PHE)  
1 Tbs. Pickle Relish, Sweet (any brand—2 mg PHE)  
2 stalks Celery, diced (16 mg PHE )  
3 Tbs. red onion, diced (7.5 mg PHE )  
4 Tbs. Mayonnaise (Kraft light Mayo— 24mg PHE)  
Tortillas (Cambrooke Foods Tortilla - 4mg per whole tortilla)  
Lettuce (varies on type and serving size)

### Directions

Rinse jackfruit several times and squeeze out excess liquid.

In a medium saucepan combine the drained jackfruit and broth. Using a potato masher, fork, or similar tool, smash the jackfruit a bit.

Simmer over medium heat for approximately 30 minutes or until most of the liquid has cooked down. Mash a couple of times during the cooking process to allow the broth to better penetrate the jackfruit.

Cool jackfruit completely. At this point you can refrigerate or freeze the jackfruit for future use or make the spread.

This will yield approximately 1-1/2 cups jackfruit, which can be used to replace cooked, shredded, chicken.

In a bowl, combine jackfruit, celery, pickles, onion and mayo.

The final mix yielded about 2 cups prepared jackfruit spread.



Dear Phebea,

# What's the point of continuing clinic visits?

*Dear Phebea,*

I don't understand the point of clinic visits. I feel like the doctor just tells me what I already know, and the dietitian only asks what I ate. Why do I have to go to them? Why do they care if I come?

*Sincerely,*

*Confused by Clinic Visits*

*Dear Confused by Clinic Visits,*

Good question! As you get older and you've seen your doctor a lot, I can understand why clinic visits may not seem helpful. They are important though! It's a opportunity for you to check in with your doctor and medical team. It gives them a chance to hear about how you're doing. It's also an opportunity for them to review your health. The team wants to hear about how you're doing in school, at work, or how your mood is. It helps them assess your brain health. The team checks your growth over time. This helps them determine if they need to adjust your medical formula or work with you on your diet to increase or restrict your protein intake. The team also wants to meet with you to see how you are managing your PKU or metabolic condition. If you are having challenges, they try to help find ways that they can help you do it better. They also try to help educate you about your condition such as what the best blood levels are, what are we learning about the condition as research improves, and what possible new treatments are out there. The metabolic team also may have worked with other patients dealing with similar situations, so they may be able to help you strategize different actions to take to improve your management. Your doctor also has to write a prescription for your metabolic formula annually. Not every state provides metabolic formula to patients with metabolic conditions. In Illinois, we are lucky to have a formulary that provides formula at no cost to patients. It's important to attend clinic annually, so that the state can continue to provide you with your metabolic formula.

To make sure you get the most out of your clinic visits, I would recommend that you take time before going to your clinic visit to think through any questions that you may have. Write your questions down and come prepared. The week before, email or keep track of your diet record for the dietitian. This preparation may also help you think of additional things that the medical team can help with. Clinic visits are meant to be useful for everyone. It's so your medical team can see how you're doing, and it's also meant as an opportunity to see how they can assist you. Speak up and ask questions!

*Sincerely,*

*Phebea*



# Andrew Craig Scholarship Winners

See what our scholarships winners are up to, and how they handle having PKU!

## Michelle Brandon



PKU has taught me at a very young age to be aware and mindful of how it feels to be inside my body. Certain foods can make you feel great and other can make you feel icky. And this applies to everyone, with or without PKU. Because of that, my interest in nutrition and culinary arts skyrocketed. I love cooking new and exciting dishes from all corners of the world. Plus, when I cook, I am certain of every ingredient that is in the dish, including my favorite ingredient... pure love! :)

Living with PKU, having a wonderfully supportive family and network of friends, being involved with the PKU community, helping others and most of all taking initiative in helping myself is where my passion of the power of positivity root from. I constantly reaffirm and focus on the positive side of life each and every day. It's always better to focus on what we "can" do rather than what we "can't" do when thinking of PKU! Maybe I had to learn it the hard way way...but now I apply that to everyday life and having this perspective helps me so much! I believe each and every person has the power within to manifest and create joy and success.

Currently, I am in graduate school at the National University of Health Sciences for Oriental Medicine. Oriental Medicine includes Traditional Chinese Medicine along with other healing styles and modalities from neighboring Asian cultures. Ultimately, this includes acupuncture, materia medica, shiatsu, Qi gong, cupping therapy and much more! I am ecstatic to begin to understand the layers of knowledge and apply everything I learn to help others achieve their healing prospective and a higher quality of life. I believe now is the time to educate others and take action on our health and wellness.

I consider myself being an advocate for preventative health care as a whole. Applying Oriental Medicine values into my practice is going to be an integral entity to manifest success for myself and most importantly for my patients

## Taylor Hardy



PKU has been such a big part of my identity growing up. I have been incredibly blessed in my PKU journey. It has made me realize just how lucky I am. My body is tolerable to PHE. I have been off diet since I was seven years old, but I still have to maintain my PHE levels in hopes of one day raising a healthy family. PKU has given me a different perspective on life. I struggled so much when I was younger because I was different from my friends, but as I've become older, having this genetic condition has made me value my uniqueness. There is no one else in this world exactly like me and that is pretty awesome. My PKU sets me apart from all of my friends and that's pretty cool. God has made each of us in a specific way and I am glad I am different. PKU gives me the platform to be a role model to others who are different according to societies standards. I know what it is like to feel different from others. PKU has given me the ability to be confident in who I am.

I currently am attending Illinois State University, studying elementary education. The scholarship award that I was incredibly honored to receive has helped me pay for tuition and books this semester (Spring 2016). I am so grateful and honored to have received such a generous award.

# Garrett Austin



My name is Garrett Austin and I was a 2015 Andrew Craig scholarship winner. To start, the disorder I have is Homocystinuria, which means I cannot breakdown the amino acid Methionine. I was diagnosed at the age of 5 due to new born screening not being available when I was born. Some of the characteristics of Homocystinuria that I have include dislocated lenses, pigeon chest and knock knees.

I would say that the challenges that I had to face because of it are not too different from anyone else within the community. One of the challenges that I had to overcome was dealing with harassment from other people at school, as the only medication in terms of protein supplement that I'm allowed to take because of it being the only one that the state will cover usually is called Homoniex-2. When this medication is all made and done, it resembles a brown pudding. People would harass me because of the way it looked and smelled. They would also ask me why I can't eat things like cheese and meat over and over again, and even teased me some about it. Basically, lunch wasn't always the most pleasant time. Another challenge was having to deal with those who

worked for the school and dealing with their ignorance on the subject. A third struggle was having to grow up in a house with 7 brothers and sisters and most of them being mostly carnivores.

Over the years though I have learned to ignore these type of people and their behavior as that's their choice to be ignorant and not learn about the situation. Growing up with my family of mostly carnivores, has taught me patience and restraint when it comes to food being shoved in my face that I cannot eat on a daily basis. It has gotten easier to cope with the condition with various sources of help and strength. I am lucky to have my sister Danae who knows what I am going through with this condition. I am lucky to have great friends like Dean Seppelfrick who has always been a wonderful advocate for me when dealing with doctors and related groups of people. How I came across the PKU and Allied Disorder Organization was through my sister Danae and it has been a tremendous benefit for having support.

I am currently enrolled at Waubensee Community College and I am plan on transferring to North Central College in Naperville in the fall 2016. I will be double majoring in Japanese and English. I hope to have an internship abroad shortly thereafter. Thank you to the PKU and Allied Disorder Organization for this wonderful scholarship.

**Are you in or entering college?**

**Are you looking for scholarships?**

**Do you have PKU or an Allied Disorder?**

**You may be eligible!**



**Visit pages: 20-22 of PKU Press**

**Or**

**PKUIL.org > Resources > Scholarship forms**

Dear PKU and Allied Disorder Community,

We as a board want to apologize. We haven't been transparent in letting you know where donations go, and for that we're sorry. Your donations haven't been ill spent or squandered, but you as a person in the community still have a right to know. I know personally I don't donate to causes where I don't know where the money goes, and I bet many of you are the same. So that said, this lack of transparency won't happen again. We're going to be more transparent than ever in goal publishing and updates. Thank you for your patience

The PKU board has ambitious goals for 2016 and we want everyone to participate. We're looking to raise \$30,000 this year after event costs. This is a big number, something that has been achieved before but not in the last few years. Because of this, the events we have this year are going to cost more to attend than year's prior, but these events are all fundraisers. Every event for which you purchase tickets is a donation to a 501(c) 3 charity. All that said, where is the money going this year? We have divided up the donation avenues into two causes:

- 1) Research for a cure
- 2) Lifestyle enhancement

While I think we all would love a cure, helping all who have PKU lead a more enjoyable life is incredibly important as well.

- \$10,000 of the money raised will be going to NPKUA specifically for grants to research a cure for PKU
- \$5,000 will be going to the creators of [www.howmuchphe.org](http://www.howmuchphe.org) so they can continue their good work helping us find out about the foods in our system.
- \$5,000 will be going to [www.cookforlove.org](http://www.cookforlove.org) to enable Brenda Winiarski to continue creating recipes for wonderful low phe foods.
- \$6,000 will go to scholarships for students to offset college tuition.
- \$4,000 will be going to the clinics in Illinois.

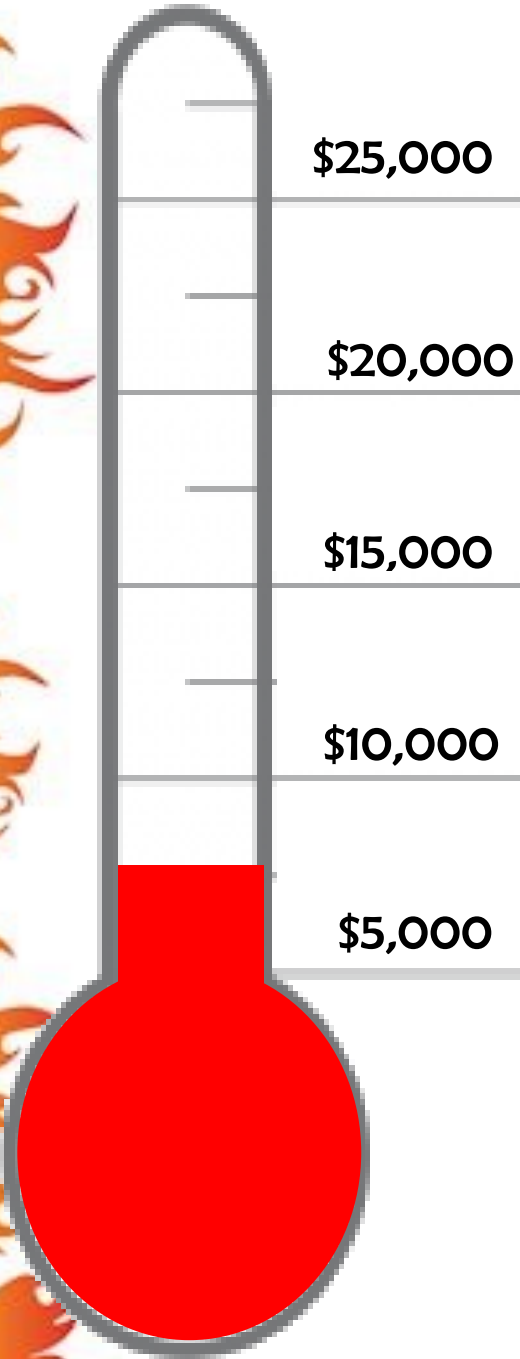
Any additional funds will be distributed evenly. This is going to be a great year, and we're very excited to share it with you. If you have any feedback or additional questions, please let us know. Once again, thanks for everything you do and we'll see you soon!

The 2016 PKU Organization of Illinois Board



# Help Spike the PHEver for a Cure

**\$30,000**



## How will it be spent?

\$4,000 Clinics

\$5,000 CookforLove.org

\$5,000 How Much PHE

\$6,000 Scholarships

\$10,000 NPKUA Research Fund

## 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

# SAVE THE DATE

April 9, 2016

BioMarin Cooking Class

DeKalb, Illinois  
NIU-Wirtz Hall

Register at: [PKU.com](http://PKU.com)

May 14, 2016

Family Fund Day

Aurora, Illinois  
Blackberry Farm

Register: [PKUIL.org](http://PKUIL.org)

June 11, 2016

Parent Café

Lisle, Illinois  
Grounds for Hope Café

Register: [PKUIL.org](http://PKUIL.org)

July 28-31, 2016

NPKUA Conference

Indianapolis, Indiana

The Westin Hotel

Register: [npkua.org](http://npkua.org)

August 31, 2016

Andrew Craig  
Scholarships applications  
deadline.

Form available at  
[pkuil.org](http://pkuil.org) > resources

September 23-25, 2016

PKU Family Camp

Hudson, Illinois  
East Bay Camp

Register: [PKUIL.org](http://PKUIL.org)

October 2, 2016

Carlos R. Galvez Memorial  
Golf Tournament

Lockport, Illinois  
Broken Arrow Golf Club

Details to follow

October 15, 2016

Wine Tasting &  
Silent Auction

Chicago, Illinois  
Letizia's Natural Bakery

Register: [PKUIL.org](http://PKUIL.org)

November 12, 2016

PKU IL Annual Meeting

Oak Brook, Illinois  
Hilton Oak brook  
Conference Center

Register: [PKUIL.org](http://PKUIL.org)



# PKU Organization of Illinois Family Fund Day

Annual Fundraiser for a Cure!  
National PKU Alliance

Saturday, May 14, 2016

RSVP at: [www.pkuil.org](http://www.pkuil.org)

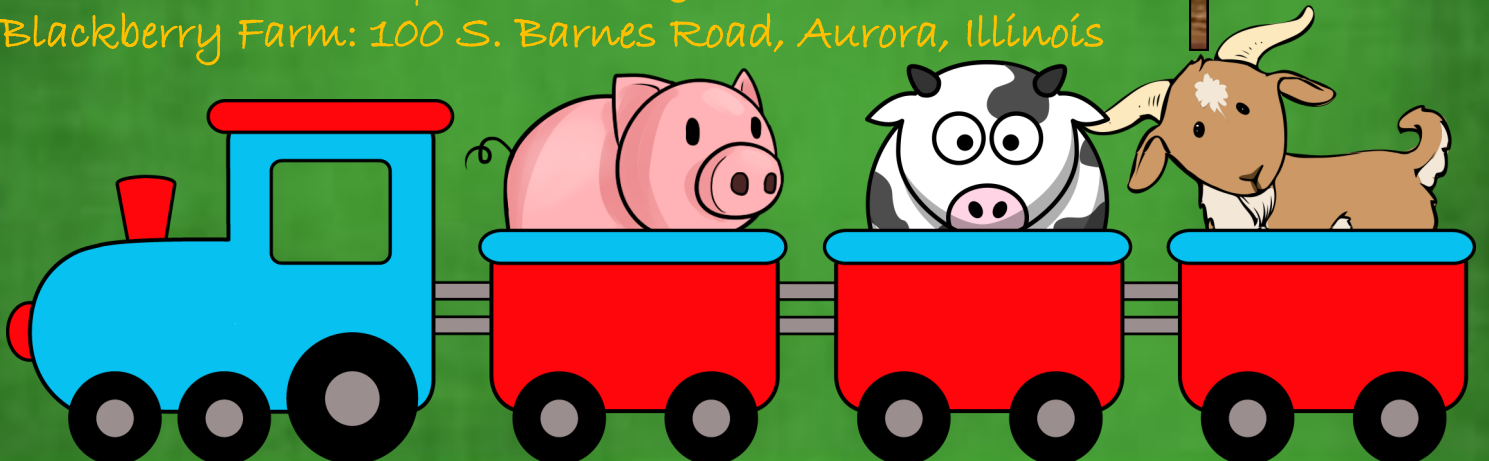
RSVP Deadline: Saturday, May 7, 2016



Includes:	Before April 21	After April 21
Admission & lunch		
Adult	\$32	\$40
Child	\$24	\$30

Questions? Contact: [pkuillinois@gmail.com](mailto:pkuillinois@gmail.com)

Blackberry Farm: 100 S. Barnes Road, Aurora, Illinois





# *Parent Café*

*At Grounds for Hope Café within Trinity*  
*2701 Maple Avenue, Lisle, Illinois 60532*

Presented by PKU Organization of Illinois

Saturday, June 11, 2016

9:30 – 11:30 am

Bring your kids and stop in for a tea or coffee. Network with other parents of those with PKU or Allied Disorders, and speak to mothers with PKU. Exchange tips and tricks with other parents.

Meet with low-protein vendors and learn what's new, taste product samples, and ask questions to help understand what's available.

Kids can play in the 3 story playhouse and ball pit, while you network with families and doctors.

- Please bring socks
- PKU Snacks will be provided
- Every family will receive a gift bag for every family to help support the day-to-day low protein lifestyle



*Questions: Contact [pkuillinois@gmail.com](mailto:pkuillinois@gmail.com)*

*RSVP by June 1, 2016 at [PKUIL.org](http://PKUIL.org)*



# FAMILY CAMP

**September 23-25, 2016**

East Bay Camp

24248 Ron Smith Memorial Hwy. Hudson, Illinois 61748



**Save  
the  
Date!**

Details to follow via Constant Contact and Website!

- Arts and Crafts
- T-Shirt Painting
- PKU Bracelets
- Nature Collage
- Relay Races
- Scavenger Hunt
- Capture the Flag
- Charades
- Indoor Swimming!
- Fishing Contest
- Bonfire
- Camp Fire Songs
- PKU S'mores
- Health Activities
- Make your own Trail mix
- Healthy food choices
- Campfire Cooking
- And more!

PKU Organization of Illinois cordially invites you to:

# Wine Tasting & Silent Auction

Saturday, October 15, 2016

5 to 9 pm

## Letizia's Natural Bakery

2144 West Division Street, Chicago, Illinois 60622

Come join us for a night of wine, heavy hors d'oeuvres, and participate in our silent auction. We will also be having a Wine Raffle!

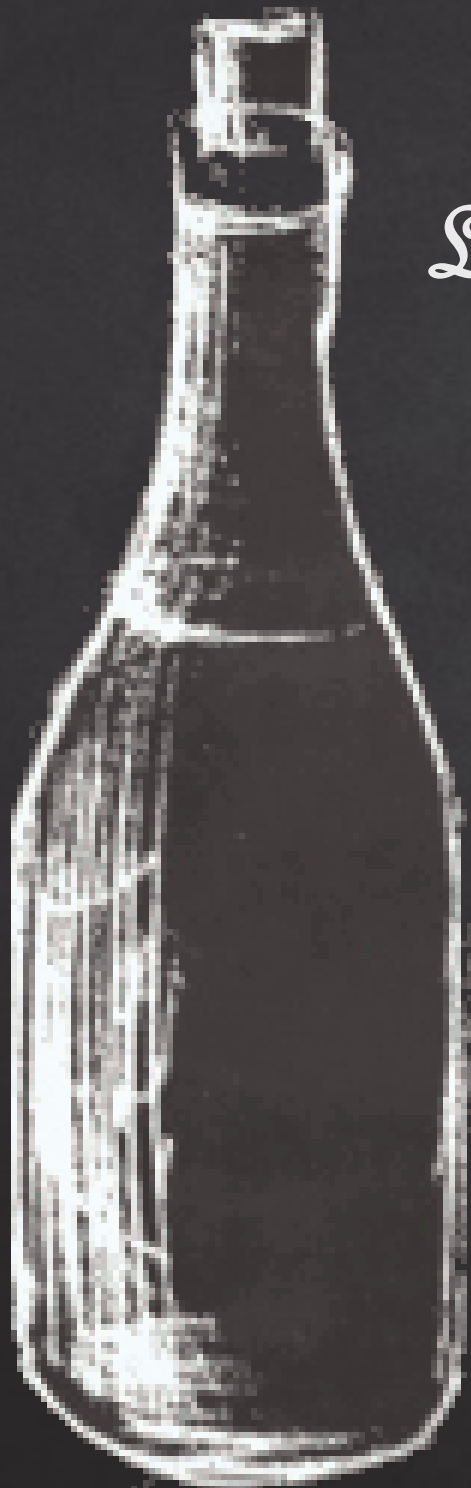
Proceeds will go to Scholarship winners, Parent Café, and Community Education Outreach.

Advanced ticket(s): \$50 per person, \$75 per couple  
Tickets at door: \$50 per person—no couple discount

Tickets may be purchased at [PKUIL.org](http://PKUIL.org)

Monetary donations and auction items are greatly appreciated!  
Please email us at the address below if you have auction to donate!

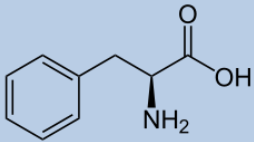
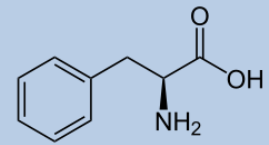
Questions? [pkuillinois@gmail.com](mailto:pkuillinois@gmail.com)





Meet our

# PHEnomenal



Board



My name is Danae' Bartke. This is my third year on the board, but my first year as the board President. I have an allied disorder Homocystinuria. I have the same low protein diet restrictions, but can't break down an amino acid called Methionine. Since joining the board, I have been helping organize and publish the PKU Press and creating the flyers for event's such as the Family Fund Day, Parent Café, and Annual Meeting. I will continue to take part in the PKU Press and the flyers, but also will be organizing the Annual Meeting. I look forward to helping promote and arrange the many events we have in the upcoming year!

My name is Grant Smith. This is my 4rd year on the board and first year as Vice President. I have a 4 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.



Andrea Hall, I'm the Treasurer of the PKU Organization of Illinois. I've been treasurer for 3 and a half years. It has been a great experience and community to be part of. I got connected to PKU through my daughter (5yrs), who has the disorder. My goal while on the board is to help everyone in the community to feel a sense of connection and support. I also would like to learn about anything new about PKU as much as possible.



My name is Matthew Bartke and this is the second year on the board. Last year I solely was the website administrator for PKUIL.org. This year I will continue to be the admin, but also add the title of Secretary. 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!



I'm Ami Vanderhoof, mom to a very happy little 2 year old, Logan, who has PKU. 2016 is my first year serving on the board, and I couldn't be more excited! I'm looking forward to organizing a fun and engaging Parent Café, an event which has introduced me to so many amazing people and lifelong friends for both Logan and myself, 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 Pam Kowalczyk. This is my 5th year on the board and am sharing a seat with my husband, Ben. I have served as Vice President as well as President in previous years. This year I am excited to be the camp director and will also be handing the scholarships. My goals for this year is to provide an excellent family camp for those affected with PKU and Allied Disorders. I will be looking for volunteers this year to help with camp since this is such a big undertaking. I also plan to continue to network for the organization .







My name is Kim Kowalczyk and I am currently a Physician Assistant in Pediatrics 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 inspired me continue my involvement in this field. Now, as the Illinois Representative for the NPKUA, I am excited to partake in matters revolving around legislation, research, and social support directly impacting PKU children and adults. I am honored to have been given this opportunity and I look forward to giving back to the very same PKU community who positively influenced my career goals in medicine.

My name is Dean Seppelfrick and this is my first year on the board. I became interested in the PKU Organization when Danae' Bartke first found out about it. I saw the impact that it made on her life, and have wanted to help since. We are very grateful for the help and education they have offered us! I will be helping organize the Wine Tasting, and our first Beer Garden. I also will be writing the grants that help us in much of our community outreach and events! My goal while on the board is to help raise funds, and help educate the community as a whole about PKU, Homocystinuria and the other Metabolic Allied Disorders.



My name is Eric Sartain. I have been on the PKU Organization of Illinois Board since 2011. I have PKU and also happen to be a chef. My job on the board is to give inspiration for new low protein food ideas through recipes and low protein cooking demonstrations. My goal for the following year is to continue inspiring people to try and create new tasty low protein foods.





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.



I'm Joseph Bonucci. I live in Princeton, IL; I'm 26 years old. I have Homocystinuria, aka HCU. I was born prior to the newborn screenings standard, so I hadn't been aware until a few years after I was born. I've been on Hominex 2 and Cystadane-betaine, since diagnosis as prescribe by Dr. Wong. Also, I have diabetes; to balance. I focus on higher amounts of carbs with large dose of humalog-novalog with a low protein focus.

## Meet our **PHE**nomenal

## Honorary Board Members

Hazel Vespa, Licensed Clinical Social Worker, retired from Lurie Children's Hospital in May, 2013. She initially worked with the PKU Clinic Teams at Children's and University of Illinois on the interdisciplinary national PKU Collaborative Study. Early in her career she participated with parents and staff in the founding of the PKU Organization of Illinois. She has been involved in psychosocial education, research and supportive work with individuals with PKU and Allied Disorders for over 45 years. She looks forward to the leadership and resources that Soo Shim, Social Worker, Division of Birth Defects & Metabolism, Lurie Children's Hospital, will offer the PKU Community. Hazel's present goal is to continue in an honorary position to enhance the current activities of the Board and identify areas where innovative programs, services and fundraising might be strengthened.





Soo Shim MS, LCSW has been in the Social Work field with twenty-five years of experience working in medical Social Work. She currently is working in the Ann and Robert H. Lurie Genetics Division as well as outpatient clinics at the main Lurie Hospital. Mrs. Shim has spent her career working in the medical field and loves supporting and advocating for patients and families. She has worked at many healthcare organizations including University of Chicago, Illinois Masonic and Northshore Univeristy Healthsystems before coming to Lurie in May 2011. At Northshore University, she held a Corporate Manager position of the four NS hospitals (Evanston, Glenbrook, Highland Park and Skokie). She has a Type 73 School Social Work certification as well as LCSW. Soo is active and is currently the Past President for the Chicago Chapter of the Society for Social Work Leadership as well as President Elect for the Illinois Society for Social Work Leadership. Soo received the Social Work Leader of the Year Award in 2014 by the state society. Mrs. Shim received her graduate Masters of Social Work degree from Columbia in New York and undergraduate degree B.S in Psychology from Washington University in St. Louis

Lauren Dwyer RD, LDN is one of the metabolic dietitians at University of Illinois at Chicago, and she also travels with Dr. Hoganson to OSF Peoria and Springfield to outreach clinics. Lauren has been with UIC for 6 years. She attended the University of Wisconsin Madison where she became interested in PKU and other allied health disorders while working with the Maternal PKU camp held each summer at UW Madison. Lauren is currently attending the University of Illinois at Chicago working towards her Masters in Public Health and Masters in Business Administration. Lauren works with the IBEMC collaborative study and other research studies at UIC. Lauren enjoys teaching about pediatric nutrition; she also works with CLOCC (the Consortium to Lower Obesity in Chicago Children). She enjoys being a part of educational days for families and patients, and she loves watching members of this unique community come together and connect.



Mary Lonski is one of the first diagnosed people in Illinois with PKU. Mary was not diagnosed at birth, but despite the obstacles she has faced, they have never got in her way! Mary is a wonderful asset to the board and offers a lot of support and encouragement to those on the board and to others with PKU. Mary would like to do a fundraiser by creating a CD.



# Andrew Craig Memorial Scholarship Guidelines & Procedures

The PKU Organization of Illinois has elected to award dollars for education to qualifying individuals with PKU or Allied Disorders. This year, \$2,000 scholarships will be awarded to five individuals with PKU or an Allied Disorder, who reside in Illinois, and who are enrolled in an accredited college, university, or vocational school in the fall of the upcoming school year. A student may win more than once, but not in consecutive years.

## Guidelines:

The applicant must submit a complete application and,

- Show proof that he/she will be enrolled in classes during the school year for which the scholarship is being awarded
- Have been diagnosed with PKU or an Allied Disorder
- Show proof of primary residence in Illinois
- Submit a short essay
- Will apply scholarship funds to College/University/Vocational school expenses (i.e. course fees, textbooks, room & board)

## Procedures:

- An application should be obtained via:
  - Our website [\\_\\_\\_\\_\\_](#)
  - PKU Press
  - writing to us at : PKU Organization of Illinois  
Attn: Andrew Craig Memorial Scholarship  
P.O. Box 102  
Palatine, IL 60078-0102
- The application will be available from June 1<sup>st</sup> to August 31<sup>st</sup>.
- **The application must be completed and mailed/postmarked by August 31<sup>st</sup>.**
- The application will be reviewed by the Board of Directors, and ALL applications meeting the required criteria will be presented to the Board of Directors for consideration and selection.
- The winners of the scholarships will be notified by mail & email, and are invited to attend the PKU Organization of Illinois Annual Meeting to be recognized by the Board of Directors and the PKU/Allied Disorder Community at large.



# PKU Organization of Illinois Andrew Craig Memorial Scholarship Application

Please complete ALL information requested (Print clearly or Type)

Completed form is to be mailed by August 31<sup>st</sup> to:

PKU Organization of Illinois  
Attn: Andrew Craig Memorial Scholarship  
P.O. Box 102  
Palatine, IL 60078-0102

## **APPLICANT DATA:**

Name: \_\_\_\_\_  
                    First                                    Middle                                    Last

Birth Date: \_\_\_\_\_

Permanent Mailing Address: Street: \_\_\_\_\_  
  City: \_\_\_\_\_  
  State: \_\_\_\_\_  
  Zip: \_\_\_\_\_

Contact Telephone Number: (\_\_\_\_\_) \_\_\_\_\_  
  (Area Code)

Current Email Address: \_\_\_\_\_

The undersigned hereby acknowledges that the prescribed criteria for eligibility for award of scholarship funds of the PKU Organization of Illinois have been met, and that the information provided within this application is correct.

Applicant Signature: \_\_\_\_\_

## **COLLEGE/UNIVERSITY/VOCATIONAL INSTITUTION DATA:**

Name of Institution: \_\_\_\_\_

Address of Institution: \_\_\_\_\_  
                                    (City)                                    (State)                                    (Zip)

Month and Year of first semester attended: \_\_\_\_\_

## **RELEASE OF MEDICAL INFORMATION:**

Patient: Complete the upper portion of this form, and forward to your physician who will in turn complete the lower portion. Your physician should then forward this form to the PKU Organization of Illinois. (You may wish to assist your physician by including a pre-addressed envelope).

I, \_\_\_\_\_, do hereby request and authorize  
(Name of Patient)  
\_\_\_\_\_ to release medical information indicating the  
(Physician's Name/Institution)  
Diagnosis of PKU / Allied Disorder concerning \_\_\_\_\_  
(Name of Patient)  
to the PKU Organization of Illinois Andrew Craig Memorial Scholarship Program.

(Patient Signature) \_\_\_\_\_

(Guardian Signature) \_\_\_\_\_  
(Required if Patient is a Minor)

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I, \_\_\_\_\_ do hereby attest that \_\_\_\_\_  
(Physician's Name/Institution) (Patient Name)  
has been diagnosed with PKU or an Allied Disorder.

\_\_\_\_\_  
(Physician/Institution)

\_\_\_\_\_  
(Address)

\_\_\_\_\_  
(Physician Signature)

\_\_\_\_\_  
(Date)