



Illinois PKU Press Spring 2015

2015 Annual Meeting Follow Up

Saturday, November 8th, 2014 the Illinois PKU Organization held it's Annual Meeting at Skokie Holiday Inn. The theme was "Working Together for a Cure". The meeting was very well attended, with over 100 people present.

This year's guest speaker was Dr. Kristen Skvorak from University of Pittsburg Medical Center. Dr. Skvorak is leading the way in PKU research with transplanting human amnion epithelial stem cells in the PKU mouse model. If you missed her presentation you can check it out at <http://pkuil.org/?p=7>



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You Might Be a PKUer

- * If you know that marshmallows come from animals, you might be a PKUer!
- * If you spend more time in the kitchen other than any other room, you might be a PKUer!
- * If you can actually say "Phenylketonuria" and "Phenylalanine" correctly, you might be a PKUer
- * If you know the lab technician at the hospital clinic by first name, you might be a PKUer
- * If you count every single tater tot, carrot stick, olive, green bean, etc on the plate, you might be a PKUer



My Study Abroad Experience

By Sarah Tompkins

This past summer, I went on the trip of a lifetime. I studied abroad in Ecuador for six weeks through a program with the University of Illinois at Urbana-Champaign. I stayed in Lumbisí, Ecuador, which is about forty minutes outside the capital, Quito. It was terrifying at first, but it ended up being one of the most enriching experiences I have had yet.



I was scared to leave home, especially since I had never been out of the country. I couldn't imagine myself far from home for a long period of time because of my PKU, because it is difficult to plan out how much formula to take, what food to bring, and take into consideration how I am going to bring it all. However, when I first learned about studying abroad in Ecuador, I thought that this was for me, but how could I do it with my PKU? The program was for six weeks, and I would be able to learn about the culture. I would teach ESL in a summer camp for ages 7-14. I want to become an elementary education teacher with a focus on Spanish, so I really was interested in the program, but really worried about how I would be able to manage my PKU. I decided to meet with a study abroad advisor to talk about my needs with PKU and how I could be accommodated if I went. I had to set up a meeting with the Health & Safety director, the program leader, and the advisor.

When we met, I explained to them about PKU. We went over what I could do for my medicine and food. I could have shipped it, but that was too costly, and mailing in Ecuador is very slow. It was too risky for all of that to get lost as well because I knew that I would have to go home immediately if it did. I figured that my best option was bringing it all in my luggage. The formula I was taking before I left was liquid, so I had to switch to the powdered lophlex to ensure I met weight restrictions with luggage.

It was very stressful trying to fit everything in a carry-on suitcase. I was already feeling anxious leaving home for a foreign country, so trying to make sure I could fit everything I needed made me incredibly tense.

It probably was a bad idea to wait the night before to pack, but I did it. I did not sleep at all that night before I left and at 4:30 in the morning, I made my way to O'Hare airport. I remember crying saying that I didn't want to go anymore.

That first night in Ecuador made me so happy that I did. One of the first things I explained to my host family was my formula and food. I made a list of everything I could eat and what I could not. I showed them the powdered Lophlex. I said that I needed to take this a lot throughout the day. I tried asking for boiled water to mix the powdered Lophlex but I could not remember how to say it in Spanish, so I asked for "agua caliente" instead. It turned out, as my host mom explained, that the community had a way of getting purified water to give to the families living there. I was still scared though and my host mom could tell I was really nervous. After talking for over two hours, my host dad and twin 12 year old host siblings said they were going to bed. My host mom

looked at me and said, “Todos somos familia. No te preocupes.” It means we are all family and you do not have to worry. It was probably the best thing I heard and it instantly relaxed me and took away all the anxiety I felt before leaving.

While I was there, I was able to visit the capital, Quito. I saw many beautiful cathedral churches. I was able to visit the Ring of Fire! I climbed an active volcano named Cotopaxi. I visited an indigenous community called Huasalata, where I stayed in a hostel with my study abroad group. I visited Otavalo, which has a huge flea market that really attracts tourists. I was really able to put my Spanish to use there and get some good deals on items. I also stayed in another hostel in Baños. Baños is known for its hot springs and is a heavily traveled tourist area. The hot springs weren't that great, it was like a hot tub. While there, I was able to experience the night life there and it was so much fun. I went on a tour to see seven different waterfalls. I visited a zoo and was able to see many tropical animals. I also visited Mitad del Mundo, the center of the earth, and can proudly say I was at the northern and southern hemisphere at once! I also saw my first rainforest in Mindo! I was able to catch huge butterflies and go river rafting. All of these excursions were carefully planned so that I could be accommodated with my program leader, so it was made simple to manage my PKU. My program leader would inform me in the beginning of the week about weekend excursions and was very helpful with planning on what I should do.

Some difficulties that I did have while abroad was trying to talk to my host mom about my food. She was the one to prepare my meals, but I did not think she quite understood portioning my food considering Ecuador uses the metric system. I did not know how to explain it in metrics. At times, I thought she was offended that I didn't eat some of her cooking. Any problems I had with regards to my PKU, I went to my program leader. My program leader would have to explain to my host mom about portioning my food and she would go over with her what was safe to eat for me. I never felt comfortable

talking about my disorder in Spanish because I didn't feel like I could clarify it well enough, so I would go to my teacher if I didn't think my host family understood.

When we would go on excursions where I was away for the weekend, I had to prepare what food to take because I did not know what was always going to be available. I did at times eat my snacks, like the freeze-dried fruits I packed since there was not much to eat for me. My host mom would give me a lot of fruit to take with when we would go. It was always fresh! That is definitely one thing I miss is that the fruits and vegetables were always fresh.



All of this was in part made possible by Benjamin A. Gilman International Scholarship Foundation. I received a \$3,000 scholarship, which covered my all of the expenses while studying abroad. As part of being a recipient, I had to complete a Follow-On service project. I decided to write about my experience with PKU. I really want to thank Gilman International for accepting me and to my doctors who helped me with planning and guide me through this. This experience has helped me feel more capable of traveling and the want to do it more.

If anyone has any further questions about studying abroad, feel free to contact me!

I can be reached at this email. sarahtomkins@hotmail.com



Recipes from Chef Eric Sartain



Pasta with Green Olive and Eggplant.



Ingredients:

1 package of your choice of pasta
2tbls olive oil
2 cloves garlic
1 large eggplant, about 3/4pound
1/2 cup green olives
1/2 cup lemon juice (fresh)

Method:

- 1) Cook pasta in salted water, strain and return to pot to keep warm.
- 2) Heat oil in a skillet sauté garlic, 30 seconds, turn heat up to medium high add eggplant and sauté for 6 minutes until tender.
- 3) Next add lemon juice, olives, parsley and season with salt and pepper. Lastly stir in 2 pats of butter, about 1tbls. Toss with pasta.

Serves: 4

Phe: about 200 per recipe, about 50 per serving.

Toasted Eggplant Dip

Ingredients:

1 large eggplant about a pound
2 teaspoons ground cumin seed
1 fresh clove garlic
Juice of 1/2 lemon
2tbls extra virgin olive oil
2TBLs chopped cilantro
(your favorite PKU crackers,
or toasted garlic PKU bread)

Method:

- 1)Preheat oven to 425
- 2) Prick the skin and bake 45-50 minutes until skin is blistered and soft
- 3) Toast the cumin in a skillet for 1-2 minutes until fragrant.
- 4) Cut open the eggplant and cut or scoop the inside for the eggplant out. Finely chop or place in a food processor and blend leaving some texture. Add remaining ingredients and stir season to taste.



Serves: 4

Phe: 155 per recipe, about 40 serving.

“Placental Stem Cell Transplant Improves PKU Symptoms in Mice”

A Follow up letter from Kristen Skvorak, PhD

PKU Organization of IL Update

February 5, 2015

First, I'd like to start by saying it was wonderful being able to speak and answer questions for so many of you at the PKU Organization of Illinois meeting in November. My collaborators and I are very excited to see cell transplantation become a viable therapy for PKU, which we have made big steps towards achieving in the past few years, and it's amazing to know so many share that excitement. And of course, I always welcome an excuse to go home to Chicago! Next time I only hope it's a little warmer.

At the conference I discussed our rationale for treatment with human amnion epithelial stem cells (hAEC), which are pluripotent stem cells isolated from human placentas following a full term birth. *Pluripotent* means they have the ability to become any cell type (i.e. blood, heart, liver, etc.), just like embryonic stem cells. However, these cells do not suffer the same concerns as using embryonic stem cells (tumorigenic, ethical concerns) or liver cells (organ shortage, tissue matching, lifelong immunosuppression). hAEC have also demonstrated the ability to “hide” from the immune system suggesting that immunosuppression may not be necessary for long term stability of the graft. Without immunosuppression, hAEC transplants into a PKU mouse model has significantly reduced circulating Phe (60% improvement), and corrected Phe levels in the brain. In addition, substances in the dopamine pathway were also corrected following transplant, as were several amino acid neurotransmitters. These results are *very* exciting, but these studies are still only short term – 100 days post transplant.

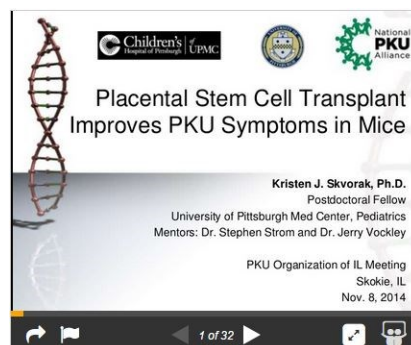
To prove stem cell transplantation is an efficient and effective treatment for PKU, we must now also prove long term correction, which is the focus of my recently awarded National PKU Alliance fellowship grant. There are two *major* events in cell transplantation: Engraftment (the donor cells must survive and become part of the host liver), and Expression (the donor cells must function normally). Both of these events must achieve maximum efficiency for treatment to be the most effective. Engraftment is the first and most important hurdle. We are not transplanting many cells compared to the billions in a native mouse liver. Therefore, we need as close to 100% to engraft as possible. Transplantation is stressful to the donor cells, and our studies thus far show low engraftment percentages. Therefore, during the initial engraftment phase when cells are the most vulnerable, short-term immunosuppression may improve cell survival. Once cells are successfully engrafted and ‘happy’ in their new environment, treatment would be withdrawn. Engrafted cells now must function at high capacity to produce enough enzyme to significantly reduce PAH. To achieve this, we plan to investigate PAH enzyme stabilizing treatments, such as Biopterin. In addition to these proposed studies, I will also be collaborating with Dr. Steven Dobrowolski at the University of Pittsburgh investigating epigenetic changes in PKU and maternal PKU syndrome.

I am looking forward to a lot of exciting things happening in PKU research in 2015. I promise to keep you informed on any new relevant publications and any significant updates about the Clinical Cell Transplant Lab at Karolinska Institute in Sweden.

~Kristen Skvorak, PhD

Did you miss Dr. Skvorak's presentation at the Annual Meeting, or would you like a refresher?

Visit our slideshare at: <http://www.slideshare.net/PKUIllinois/pku-il-2014-skvorak-copy-with-annotation>



Andrew Craig Scholarship Winners

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

Leann Buzzard

My name is Leann Buzzard and I am twenty-one years old. My parents found out a few weeks after I was born that I had PKU and I've been on the low protein diet ever since. I'm currently a senior University of Detroit Mercy nursing student. I'm working as a certified nurse assistant in both Illinois and Michigan and I am about to start my last clinical rotation in school. After that it'll be non-stop studying until I take boards after graduation.

Growing up I played soccer, softball, and ran track. I've always tried to do my best in school and with my studies. I've currently been on my schools Dean's List for three years. I've grown up never wanting to use PKU as an excuse and never viewed it as a reason to keep me from succeeding. Of course there were times when I've struggled though and still are (with the diet, being comfortable answering others questions and concerns,

expenses). Some days it's trying but most days I embrace PKU completely. PKU has blessed me beyond all measures. Living with PKU has given me life lessons that instilled in me positive attributes like confidence, empathy, humility, and strength. It is through this foundation I plan to grow as a registered nurse.



Alicia Kimbrell

I grew up in Bloomington, Illinois and I am currently a freshman at the Indiana University in Bloomington, Indiana. I am in the exploratory program, to help me decide on my major. I am initially looking into Graphic Design or Informatics as possible choices. I plan to earn a Bachelors degree and use this to obtain a job in whatever field of study I end up choosing.

With the help of my parents, doctors, and dietitians, I have learned to manage my diet as I have grown up. They have helped me learn about food choices, and quantities needed to maintain good Phe levels. I am now managing my diet as I begin a new life in college.

Even though having PKU can be difficult and frustrating at times, I haven't let it hold me back from anything. In high school, I was on the diving team, the school cheerleading team, and a competitive club cheerleading team. I went to the high school state championship twice for diving, and my competitive cheer team competed at the World Championships in Orlando, Florida in 2014. I often think about how if I didn't follow my diet, I would not have been able to participate in any of those activities and I definitely wouldn't have done well in school.

Having PKU has taught me a lot of valuable lessons throughout my life. It has taught me that no one chooses the way that they are, just like I didn't chose to have PKU, so I am understanding of people who are different. PKU has in a way made me a stronger person. I have gained self-control by learning to resist the foods that I cannot eat, which has been beneficial in other aspects of my life as well.

Through participation in the activities of the PKU Organization of Illinois, I have gotten to meet a lot of amazing and inspiring people, and even lifelong friends that I never would have gotten the opportunity to meet if it wasn't for PKU. I am also a lot more health conscious of the foods I am eating, which is something that not all teens my age think about. I think that has been very helpful for me in order to maintain a healthy lifestyle as I've gotten older. In addition to all that I've learned, I feel that I have helped to raise awareness about PKU when I explain to people why I can't eat certain foods.

Thank you very much for awarding me a scholarship at the annual meeting



Haley Walsh

I am completing my first year at McHenry County College, and will stay attending MCC until I earn my Associate Degree. My major is going to be in Law. I am looking to specialize in divorce and children special cases, and possibly estate matters. Apart from taking college algebra, biology, English composition, and other needed courses, I have taken a special interest in the social sciences. I have enjoyed studying these immensely, and plan on minoring in Psychology. Not only is it interesting and enjoyable, but it will also help me in my career in Law. Understanding is the first step to helping.



Between college, homework, studying, and work, sometimes it can get overwhelming, but my diet is my number one concern. Without it, I would not be able to do as well as I am in school. I make sure that on Sunday, I make a large amount of homemade low-protein foods for the week to come. Outside of that, I will also have low-protein foods like Cambrooke's and Aprotin products. Besides those, vegetables and fruits always make great snacks! It is always helps to keep in mind, there is never just one way to eat a vegetable or fruit, and seasonings to any dish make a world of difference. New recipes are forever emerging, all you have to do is look one up!

Looking for scholarships?

Are you in or entering college?



Do you have PKU or an Allied Disorder?

You may be eligible!

Visit pages 19-21,

or

PKUIL.org > Resources > Scholarship Forms

Calendar of Events

April

What: Grocery Store Tour

When: Thursday, April 16, 2015
6:00 PM - 9:00 PM

Where: Cub Foods
403 N Veterans Parkway
Bloomington, IL 61704

Rsvp: @ www.pkuevent.com/blo
Or call 855-PKU-CALL

May

PKU Awareness Month

What: PKU Family Fund Day
When: Saturday, May 16, 2015
Registration 9:45 am
Event 10:15 am - 1pm

Where: Cosley Zoo
1356 North Gary Avenue,
Wheaton, Illinois 60187
RSVP: @ PKUIL.org by May 5th

June

What: Parent Café

When: Saturday, June 6, 2015
10 am to noon

Where: Grounds of Hope Café
within Trinity
701 Maple Avenue.,
Lisle, Illinois 60532

RSVP: @ PKUIL.org by May 30th

July

What: Nutricia Cooking Class

When: Saturday, July 25th, 2015
Time: TBD

Where: 95th Street Center.
2244 West 95th Street,
Naperville, IL 60540

RSVP: Details to follow via
PKUIL.org & Constant contact

August

Andrew Craig Memorial
Scholarships Due August 31st

Details with in Spring PKU Press

Also available at
PKUIL.org > Resources >
Scholarship forms

September

What: PKU Family Camp

When: TBD

Where: TBD

RSVP: Details to follow via
PKUIL.org & Constant Contact

October

What: Wine Tasting

When: TBD

Where: TBD

RSVP: Details to follow via
PKUIL.org & Constant Contact

November

What:

PKU Illinois Annual Meeting

When:
Saturday, November 7, 2015

Where: TBD

RSVP: Details to follow via
PKUIL.org & Constant Contact

Would you like to host an event?

Possible ideas

- Cookie Exchange
- Low Protein Barbeque
- Golf Outing
- The ideas are endless!

Contact: PKUillinois@gmail.com

You're Invited!



GROCERY STORE TOUR

You are invited to an interactive tour of PKU-friendly foods at your local Cub Foods.

- Learn which foods at your local grocery store are PKU-friendly
- Meet others with PKU in your area
- Hear Laura Jeffers, MEd, RD, LD from the Cleveland Clinic speak about "Improving Protein Nutrition."

WHEN:

Thursday, April 16, 2015
6:00 PM - 9:00 PM

WHERE:

Cub Foods
Eastland Commons Shopping Center
403 N Veterans Parkway
Bloomington, IL 61704

PKU.com

REGISTER NOW

To reserve your space, visit www.pkuevent.com/blo or call 855-PKU-CALL (855-758-2255)

This special event is designed for people with PKU and their families.

Childcare will not be available during this event. Limit of three family members or friends per each person with PKU.

There is no cost to attend this event. It is sponsored by BioMarin Pharmaceutical Inc.

BiOMARIN

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USR0.0672E-NOV2014



PKU Organization Family Fund Day at

Fundraiser for National PKU Alliance

**COSLEY
ZOO**

A Pretty Wild Place

Saturday, May 16, 2015

Join us for:

50/50 Raffle

Up-close Animal Encounters

Walk the Zoo

Free lunch provided

Meet various Vendors

Yard Games

List of Events:

9:45-10:15 Registration
* \$25 Suggested Donation per family

10:15-11:30
Children Activities

Meet the Vendors

Walk the Zoo

11:30-12:30

Lunch

50/50 Raffle

12:30-1 Animal Encounter

RSVP Deadline : Tuesday May 5, 2015

Questions? Contact pkullinois@gmail.com

Cosley Zoo: 1356 North Gary Ave. | Wheaton, Illinois 60187

PARENT CAFE



Saturday, June 6th

10am to 12 noon

Bring your kids and stop in for a tea or coffee and network with other parents of those with PKU, mothers with PKU!

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

Registration is free, please preregister at:

grounds4hope.com/newregistration.php

- Please bring socks!
- PKU snacks will be provided

Location:

Grounds for Hope Café within Trinity

2701 Maple Avenue.

Lisle, Illinois 60532

Presented by:

PKU Organization of Illinois

Questions? Contact pkuillinois@gmail.com



RSVP by May 30th, at PKUIL.org

Dear PheBea-

Could being off diet alter how I feel?

Dear Phebea,

I have been off the PKU diet for ten years. I started trying new foods, and then I stopped taking my formula or going to clinic. Recently, I have not felt like myself and others have also commented that I have been acting different. I am having a hard time concentrating at work and I find it difficult to make decisions. I guess the best way to describe my experience is that I feel like my thoughts are cloudy, and I can't seem to remember things as well as I used to. Is this related to my PKU?

-Head in the clouds

Dear Head in the clouds,

You are not alone. I have received many complaints from others describing the same symptoms. Adults with PKU, who were taken off formula as young adults, can develop difficulties with memory, attention span, sleep disturbances, and mood changes, such as depression and anxiety. In the past, care was discontinued once children with PKU reached adulthood. It was believed that once the brain was considered fully developed, adhering to a low protein diet and monitoring phenylalanine levels was unnecessary. Persistent, high phenylalanine levels can affect brain function regardless of age. Currently, it is recommended that everyone with PKU now follow dietary guidelines for life to keep blood phenylalanine levels in the optimal range of 2-6 mg/dL to diminish these unfavorable side effects. Returning to a low protein and low phenylalanine diet can be challenging. It is a difficult decision after years of relaxation, however, the increase in medical food options and formula have changed drastically in the last 10 years. There are protein bars, ready to drink flavored pouches, juice boxes, and single serving packets to have when you are on the go. There are also new medications available. Additionally, there are numerous organizations that offer patient assistance programs for adults to decrease the financial burden to treat PKU. Visit the adultswithpku.org to explore the many ways others can offer support. Your metabolic geneticist and dietitian can review with you all your potential options. It is never too late to return to diet! Your metabolic clinic is always happy to hear from you!

-Phebea

Have you Subscribed to How Much Phe?



Hello PKU Community,

Many of us have come to rely on the Low Protein Food List for PKU. Stop and think for a moment about what your life or your child's life would be like without the food list. Because the food list is so vital to our community, National PKU News has launched two new programs that will not only keep the food list alive, but allow them to update and improve it at a much more rapid pace: HowMuchPhe.org and the Lab Analysis Program.

Seriously, this How Much Phe site is the greatest invention ever.

Molly, age 14, CPKU

WHAT IS HOW MUCH PHE?

HowMuchPhe.org is a brand new subscription program that allows users to quickly and easily find phe, protein and calorie information on any food in the Low Protein Food List for PKU via any mobile or other device that connects to the internet. This could be a smart phone, iPod, iPad, or a laptop or home computer. It also allows users to instantly calculate phe content based on portion size, taking the frustration out of having to do the math. It behaves like an "app" that can reside on your mobile device just like any other app. So at last, phe information is readily available whether you are at home, in a grocery store, on a trip, at work, or at school.

How Much Phe is an invaluable resource. I can quickly and easily calculate phe and caloric value for any serving size. It has immensely simplified the day-to-day management of my diet.

Nicole, on managing Maternal PKU

WHAT IS THE LAB ANALYSIS PROGRAM?

While the Low Protein Food List for PKU contains over 6,000 foods, new foods are introduced, recipes are changed, and foods are discontinued by the hundreds each year. In addition, many of the baseline values provided by the USDA are based on decades-old testing and may be inaccurate. PKU News has developed a lab testing program that will allow us to provide accurate, up-to-date phe content data to the PKU community--but they can't do it without your support.

Please go to HowMuchPhe.org to find out more about the program and its capabilities, review the demo videos, and subscribe (just \$45 per year: that's just 86 cents a week!). National PKU News is currently expanding the capabilities of How Much Phe to include diet tracking and other features that will enhance its value. Revenue from howmuchphe.org will be used to improve the program, maintain and update the food list, and fund the new food testing program.

Text, email, or call your friends and let them know this is available to make their lives MUCH EASIER.

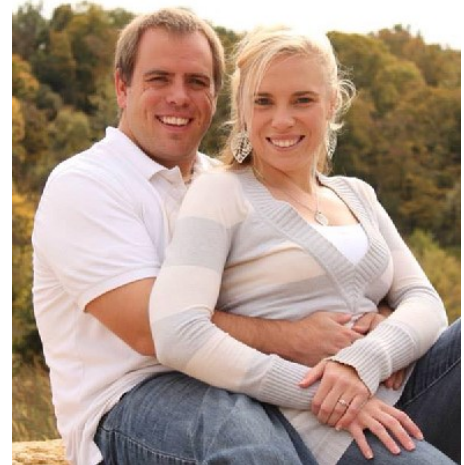
Patty, PKU Parent

WHAT ELSE CAN YOU DO TO HELP?

When you subscribe to HowMuchPhe.org, you can opt to add a donation to your subscription. This donation will be entirely tax-deductible and will help National PKU News reach its goals. Your friends and family can help too. Ask them to visit <https://howmuchphe.org/user/support> and become Community Supporters. By becoming ongoing contributors to National PKU News, they build the capacity of a vital resource for the entire PKU Community.

Meet Your 2015 PheNominal Board Members

Hello! My name is Pam Kowalczyk. This is my second year as president for the PKU Board of Illinois! Last year was a great learning year for our team. With that year of experience under our belts, I am looking forward to more events, excellent communication and greater positive involvement from the PKU community. Being an individual with PKU, I want to make sure we continue to have educational events as well as opportunities to fundraise to continue to support those in need and continue our programs to further educate ourselves in the ever-changing world of PKU and allied health disorders.



My name is Ben Wagner. I am the Vice President of the PKU Organization of Illinois. My wife, Pam, who serves as our president has PKU. My goals for this year is to increase our communication if events between the organization and the PKU community. I would also like to see increased attendance at each event which will come through our communication and networking. We would love to see more people come out to our events and share their experiences and stories with others and learn more about the things going on



Andrea Hall, I'm the treasurer for the PKU Org of IL. I've been the treasurer for 2 and 1/2 years now. It has been a great experience and community to be a part of. I got connected to PKU through our daughter (4 yrs), who has this disorder. My goal while on the board is to help everyone in the community to feel a sense of connection and support. Also, try to educate as many of us, on anything new or what we want to know, as much as possible



My name is Melissa Sujak. I am currently the PKU Organization of Illinois Secretary. I have served on the board for the past two and a half years. My four year old son was diagnosed with PKU. Since being immersed into the world of PKU I am dedicated to providing support, opportunities for education, fund-raising for research, networking and support to the PKU community.

My name is Grant Smith. This is my 3rd year on the board. I have a 3 year old son with PKU. This year I'll be in charge of our Facebook, twitter, and constant contact messaging to the community.



My name is Matthew Bartke. This is my first year on the PKU Organization of Illinois Board. My wife, Danae' has Homocystinuria, an allied disorder. Since joining the board, I have taken on the role of web administrator. My goal while being on the board is to make everything run more efficiently. Efficiency for me means, making things up-to-date and accessible via our website. I would also like to make things easier for future board members.

If you haven't already, check out the newly designed website, go to: <http://www.pkuil.org>





My name is Danae' Bartke. This is my second year on the PKU Organization of Illinois board. 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 the Annual Meeting. My goal for this year while on the board is to increase communication between ourselves and those affected by PKU and Allied disorders. In increasing our communication, I hope to help make our events even more successful then they have been in the

My name is Haley Walsh and I am currently a freshman at McHenry County College. Along with being a full time student and working part time, this is my second year on the PKU board. I am in charge of the "PKU_IL" official PKU Organization of Illinois Instagram account. On there are a variety of low-protein food ideas and any PKU related question is more than welcome!



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.

Hello, my name is Jacob King. I have been on the PKU board for two years and I live in a small town with my wife Kristen. I have PKU and enjoy meeting people with PKU. I would like to see more cooking classes and more events for people to go and meet other people.



My name is Katie Patiewicz and it is my first year on the board! I'm a stay at home mom/full-time college student at CLC. My two kids have PKU. Drew is 6, Hailey is 5. 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.

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 fund-raising 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 University 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.



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 (www.pkuil.org/scholarship)
 - 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 1st to August 31st.
- **The application must be completed and mailed/postmarked by August 31st.**
- 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 31st 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)

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)

Stay Connected!



PKU Organization of Illinois



@pkuillinois



@PKU_IL

Instagram

Email or mail us your....

*Name: (First and Last) : _____

*Mailing Address: _____

*Phone Number(s): _____

*Email Address(s): _____

Disorder: _____

Mailing Preference: Email / Mail / Both

Email: PKUillinois@gmail.com

Website: www.PKUIL.org