



Fall

2015 PKU Press

College Experience with PKU

COOKIE

Scrumptious Recipes

EXCHANGE

CamBrooke Cooking Class

Wine Tasting & Silent Auction

Annual Meeting Save the Date

NOW SEEKING

NEW BOARD MEMBERS

Event Recaps

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Dear Phebea-



The College Experience with PKU

by Sarah Tomkins



L to R: Chef Carissa, Erica Nehrling Meador, Myself, Chef Chris

I began my college experience at community college with the hope of transferring to a four year university, but I was nervous on how I would adjust living away at school with my PKU. I had picked out two schools to apply to. I applied to, the University of Illinois at Chicago (UIC) and the University of Illinois at Urbana-Champaign (UIUC). I was incredibly excited to be accepted into both schools, so I took my next step by meeting with the dining hall staff to talk about my PKU, since I would be living at a dorm on campus. The UIUC dining hall staff were very friendly and understanding of PKU. They were incredibly thorough and organized. This really stood out to me and ultimately helped me decide to choose to go to UIUC.

I worked with the school dietician, Erica Nehrling, and the dining hall staff at the Ikenberry dining hall. I was able to get low protein food with a purchased meal plan that the university offered without any extra costs. I sent them a list of foods I typically liked and they would order it from Lil's Dietary Specialty Shop and store it in the kitchen for me. I would order a PKU friendly meal off a site that was created for students living in the dorms with food allergies and diet restrictions. I would send in an order about an hour ahead of time and would pick it up at the dining hall kitchen.

The staff were always prompt and incredibly kind. They would even go out of their way to make extra things that I did not order but knew I would enjoy, like Maddy's sugar cookies. They were always going out of their way to make sure I was being accommodated. I would meet with the chefs and dietician several times throughout the year to talk about how things were going. The chefs would try and create new recipes for me to try. I would pick recipes out of the Apples to Zucchini cookbook, and they would make it. The dietician, Erica Nehrling Meador, even followed me on Pinterest to get some PKU recipes I had found on there. The past two years living on campus have truly been the best because of the kindness and generosity of the University of Illinois at Urbana-Champaign dining hall staff. This has been one of the most positive experiences I have had living with PKU. I cannot thank them enough for everything they have done. Going away to school was a huge transition in my life, but my PKU didn't have to be. I have been able to grow as a person and take better control of my PKU as well. Thank you again to the UIUC Ikenberry dining hall staff with all your generosity and support.



Recipes from Chef Eric Sartain



Vietnamese Spring Rolls

Servings: Makes 12 Spring Rolls

43mg Phe Per each Spring Roll.

65mg Phe per each Spring Roll with 2 Tbs. dipping suace

Ingredients:

12 Rice Papers
2 cucumbers-Julienne
2 carrots-Julienne
3-4 stalks bok choy- julienne
1 head of red leaf, or Boston lettuce
(I have substituted spring mix also)
1 lb. bean sprouts
1 bunch cilantro
1 bunch mint
1 bunch basil
Sesame seed oil (optional)

Dipping Sauce:

1/2 c. Soy Sauce
1/4c. rice wine vinegar
2 Tablespoons Sugar
minced green onion for garnish
1 teaspoon red pepper flakes
a dash of sesame oil
Whisk all together



1) Have a pan or kettle of hot water at your side. In a dish that is large enough for the rice paper but not too deep, dip the rice paper into the hot water and let sit for about 20-30 seconds.

2) Pull the rice paper out and if not soft enough let sit a little longer. When you take the rice paper out it should be translucent very soft and slightly sticky. Lay it as best as you can on a cutting board or plate.

3) Lay ingredients inside of the paper as desired. The paper is fragile and will not hold to much. Lay a good pinch of each ingredient closest to your body, NOT IN THE MIDDLE. If desired you may drizzle a little of the sesame seed oil if then start rolling...

4) Next fold the outside flaps in. will tucking the ingredients with your fingers roll the rice paper to the other side, then tuck in the sides.

Ingredients:

2 lemons, zest and juice
2 limes, zest and juice
1/2 c. honey
1/2 bunch mint, chopped
1 lb. watermelon, diced
1 lb. cantaloupe, diced
1 lb. honeydew, diced
1 lb. pineapple, diced
2-3 mangoes, diced

Fruit Salsa



Method:

- 1) Combine watermelon, cantaloupe, honeydew, pineapple, and mangoes
- 2) Add juice, zest, honey and mint to taste.



Vegetable Fried Rice

1 cup Vegetable Fried Rice = 72 mg Phe

Method..

- 1) Sauté all the vegetables in a nonstick skillet in vegetable oil. After 2-3 minutes, pull the vegetables off and set aside.
- 2) Let the pan get hot again, then add the rice and sauté with a little bit more vegetable oil as needed. The rice will absorb some oil, so pay attention to how much you add. (It will get soggy if you add too much!)
- 3) Once the rice has started to fry a little bit and gain some color, add the vegetables back in and continue stir frying for 3-4 minutes or until desired cooking.
- 4) While cooking, add soy sauce and toss until most of the moisture is absorbed, the rice should take on the color of soy. You can add a little more if desired. Add a dash of sesame oil if desired for flavor right before serving.

Ingredients.

4 c. day old white rice (low protein)

1 medium onion, diced

1/2lb. peas, cut into halves or thirds

1/2lb. Mushrooms, sliced

1/2lb. Daikon,

1 medium carrot

1/2 lb. bean sprouts

1/2 c. lite soy sauce

Vegetable oil, as needed

• Items included in PHE Count

Soup Base.

- 4 C. Vegetable Stock* Free
- 1 tsp. Fresh Ginger, Grated* 5
- 1 tsp. Soy Sauce* 16
- 2 tsp. Rice Wine Vinegar* Free
- 1 tsp. Salt* 0
- 1/2 tsp Pepper* 5
- 2 C. Bean Thread Cellophane Noodles* 28

Vegetables

- 2 Tbs. Bell Pepper, diced* 3
- 2 Tbs. Carrot, sliced* 3
- 2 Tbs. Daikon or Radish* 3
- 2 Tbs. Cucumber* 2
- Mushroom or Bean Spouts

Garnishes.

- Cilantro
- 2 tsp. Basil* 5
- 2 tsp. Mint* 5
- 2 tsp. green onion* 5
- Sambal or Siracha unavailable

PKU Pho

PHE Information.

- Yield: 3 Servings
- 32 PHE/Serving
- 96 PHE/ Recipe



Cooking Instructions.

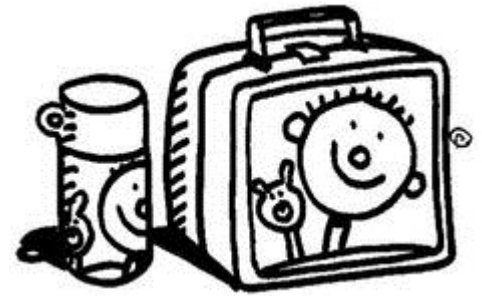
- 1) Cook bean thread noodles in water. Drain and set aside.
- 2) Bring broth to boil, add ginger, salt, pepper, soy and rice wine vinegar, then stir.

Serving Instructions.

- 1) Add noodles to individual bowl. Ladle broth over noodles.
- 2) Top with desired vegetables, herbs and garnishes. Enjoy!



Back to School with Jacob King



Spicy shoe string Jicama fries

- 1 Large Jicama peeled and spiral zed
- 2 TBS olive oil
- Slat to taste
- 1.tsp. onion powder
- 2tsp. paprika
- 1tsp. cumin

Directions:

Cut Jicama spirals into 6" lengths. Cover baking sheet with foil and spread jicama
Foil pans. Drizzle with olive oil coat evenly.
Season with spices
Bake 15 minutes at 400 degrees
Open oven and flip fries over and bake 15 min more until cooked to your liking.

Taco Salad

- 2 cups chopped or shredded lettuce
- 1/4 c. diced tomatoes or olives
- 1/4 c. low protein rice (seasoned with taco seasoning)
- 2 Tbs. Low protein cheese
- 6 Doritos chips crushed up for on top of salad
- 2-3 slices of avocado
- your choice of dressing or salsa

Serves: 2-3

70mg PHE per Serving

Spaghetti Squash Chow-Mein

- 1 Large spaghetti squash
- 1/4 cup soy sauce
- 3 cloves of garlic minced
- 1 T brown sugar
- 2 Tsp fresh grated ginger
- 1/4 tsp white pepper
- 2 T olive oil
- 1 Onion diced
- 3 stalks of celery sliced
- 2 Cups Cole slaw mix

Directions :

Cook Squash 30 to 40 Min
Mix soy sauce and garlic brown sugar ginger and pepper
Heat oil add Onion Celery cook for 3-4 min
Stir the Cabbage in cook for 1 min
Stir in squash and soy mix cook for 2 min



Roughly 21 people came out to attend our annual Parent Café



Children were able to play in the treehouse

Parent Café Follow up

On June 6th the PKU Organization of Illinois hosted the annual Parent Café at Grounds for Hope Café in Lisle. It was an opportunity for parents of children with PKU and PKU mothers to mingle with other parents while the children had an opportunity to play in the treehouse and work on crafts. PKU friendly snacks were provided and Cambrooke provided low protein foods to sample. This year was the most attended Parent Café.



Some of the yummy snacks Cambrooke provided

Dr. Barbara Burton and Registered Dietitian Heather Bausell from Ann & Robert H. Lurie Children's Hospital lead the "ask the expert" segment. They answered questions regarding updates on PKU research, treatments and nutrition management. The PKU Organization of Illinois would like to thank those who attended the Parent Café and look forward to providing further opportunities for education and community support.

Sincerely,

Melissa Sujak RD, LDN, CDE

PKU Organization of Illinois Board Secretary



Dr. Barbra Burton and Dietitian Heather Bausell leading the "Ask the Expert" segment.



Recap: Family Fund Day 2015

Saturday, May 16, 2015 the PKU Organization of Illinois held its annual fundraiser to benefit the National PKU Alliance at Cosley Zoo in Wheaton, Illinois. Despite the overcast weather, the day was a great success. Almost \$900 was raised. Roughly 100 people came out to attend, along with 5 various vendors. In attendance, was our very own Ruthie Jager, 2015's Miss Illinois!

Families started the day with 10 am registration. After registration, they were able to leisurely walk the zoo, visit vendors, and have their children partake in our children's activities. About 11:30 we had a delicious lunch prepared by Caliendo's Restaurant and a delicious PKU Mexican themed lunch donated graciously by Cambrooke Foods. Along with lunch, we also held our 50/50 raffle. After lunch, families were able to take part in our close up animal encounter, where they were able to learn about and pet a turtle, tarantula and rabbit.



NPKUA Washington DC Lobby Day 2015 Recap

Being the grandfather of Nolan Michael Sujak age 5 of Lisle IL, who was born with PKU, it was a great honor and a privilege to be asked by the PKU Organization of Illinois to represent them in Washington D.C. and lobby for the passage of The Medical Foods Equity Act along with the NPKUA. The courses of the lobbying efforts were from May 17 thru May 19. Over 25 Board members and volunteers assembled to sit down and discuss this vital Foods Bill with 78 United States Senators and representatives. Upon my arrival to the Residence Inn Arlington Courthouse on May 17, I met up with Christine Brown, NPKUA Board President, and her chief Assistant Katrina Swenson. Other Board members who attended were Amy Oliver, Melissa Perez, Steve Hunt, Rhonda Connolly, and Kristen Vanags. What a tremendous honor to meet and speak with such great dedicated people. Just sitting down and listening to them speak, I learned so much.

On May 18 after a short meeting at the hotel to discuss our strategy, we set out for Capitol Hill. I was teamed up with NPKUA Board member Rhonda Connolly from San Diego, CA. and with Bryce Comstock from The National Children's Healthcare Organization. Our first appointment took us to The Hart Senate Building, where we met



Samantha Warren, Rep. Bill Foster's legislative director



Brandon Webb, rep Robin Kelly's lead legislative

up with Mark Stewart who is the chief Healthcare Director for Illinois Senator Mark Kirk. Mr. Stewart listened to us discuss our needs and just how vital the passage of The Medical Foods Equity Act was for our children and adults who through no fault of their own were born with PKU and other types of inborn metabolic disorders. Mr. Stewart was very attentive and was shocked by the costs of not only the medical formula but also the manufactured foods that our family members have to eat every-day of their lives. I believe that by the time we left Sen. Mark Kirk's office we left with the enlightenment that we had Mark Stewart on our side.

Next up was The Longworth Building, which houses most of our U.S. Representatives. There we met Brandon Webb, chief legislative Director for Congresswoman Robin Kelly of the IL 2ND District. We found that Brandon Webb was very interested and he even committed to us that Ms. Kelly would certainly back this legislation out of committee. We left Robin Kelly's office with a new sense of purpose, we were energized. We had talked to two legislative Aides who basically committed to backing this Bill.

We stayed in the Longworth Bldg and moved down the hall to 11th District IL. Rep Bill Foster, where we met with the Congressman's Chief Policy Advisor Samantha Warren, who also showed great concern for our advoca-

cy and she promised to bring our concerns up to Congressman Foster and was sure he would back this legislation also. I live in Mr. Foster's 11th District and have talked to him on numerous occasions, so I will be following up and speaking to not only congressman Foster, but also with Robin Kelly, and with Sen. Mark Kirk. In addition, I will make contact with other Illinois congressman and women that we could not meet up with. It was a very good day, and as I stated before the dedication of all the advocates was very inspiring. It was an honor to be asked to be among these great people. I want to thank the PKU Organization of Illinois for placing confidence in me on speaking on their behalf. I look forward to doing it again and again until we can get the needed help that should be a right for all those with PKU and other inborn Metabolic Disorders.

Sincerely,
Mike Schauer

The NPKUA Representatives



Have you always wanted to visit Lil's Dietary Specialty Shop but never had the chance? Do you need new low protein food ideas & options?

You're invited to a grocery store tour at...

LIL'S DIETARY SPECIALTY SHOP!

When: Thursday, August 20th
6:30-8pm

Where: Lil's Dietary Specialty Shop
2738 W. 111th Street
Chicago, IL 60655

 Ann & Robert H. Lurie
Children's Hospital of Chicago[®]

Please join the Lurie staff as we sample some low protein foods and check out all of the fun low protein options at Lil's (www.lilsdietary.com). Feel free to invite other friends or family members! Parking is available at the store's location. Questions call 312-227-6122 or email metabolicdieticians@luriechildrens.org.



Cambrooke Presents Low Protein Pasta and Rice Workshop

Saturday, September 19, 2015
Cambrooke Foods, along with the PKU Organization of Illinois
invite you to a day of inspiring new recipes and friendly
competition.

9:30 Registration
10-12 Workshop
12-1 Tasting, Discussion and Raffle

From The Field Cooking School & Culinary Center
2029 S. Main St.
Morton, IL 61550

Space is limited, so register quickly!
Register at www.PKUILL.org



family to family

PKU Organization of Illinois
cordially invites you to:

Wine Tasting & Silent Auction

Letizia's Fiore Ristorante

2456 N. California Avenue.

Chicago, Illinois 60647

Saturday, October 3, 2015

5 to 9p.m.

Tickets are \$45 per person,
or \$65 dollars a couple.

Monetary donations and auction items are greatly appreciated!

RSVP at www.PKUILL.org
Questions? pkuillinois@gmail.com



Come join us for a
night of wine, heavy
hors d'oeuvre, and
participate in our
silent auction.

Proceeds go to
Scholarship winners,
Parent Café, and
community education
outreach.

Milestones in PKU & Allied Disorder Community

2015 Annual Meeting

Saturday, November 7, 2015

Skokie Holiday Inn
5300 W. Touhy Ave. Skokie, Illinois 60077



Meet our Highlighted Speaker:

Dr. Kendra Bjoraker



Dr. Kendra J. Bjoraker is a clinical neuropsychologist with specialized training and expertise in rare genetic diseases. She served as faculty at University of Minnesota and Children's Hospital Colorado/University of Colorado with extended studies in neurodegenerative diseases with further understanding for genetics, metabolism, white matter diseases and neuroimaging. She is a presenter, researcher and has extended publications in rare genetic diseases. Dr. Bjoraker is known nationally and internationally for her expertise in lysosomal storage diseases, peroxisome disorders and other rare inherited metabolic disorders. She is involved in multi-disciplinary research projects investigating the factors that predict and contribute to the neuropsychological and health outcomes in individuals with genetic and metabolic diseases. She recently started her own consulting business called 3:1 Neuropsychology Consultants, PLLC. Her mission is to disseminate information for disease awareness and quality of life, consult on medical and educational issues, present at conferences, seminars and family meetings, and continue research on the subject of brain-behavior relationships as it relates to each condition.

Breakout Sessions:
Our breakout sessions are led by RDs, Physicians, social work and PKU representatives. This year we are organizing our breakout sessions by age group.

Age Groups:
Early Childhood
Elementary
Middle School
High School
Adulthood
Allied Health Disorder

Children's Program
Ages 6-12



HOW DO YOU PKU ?

**Calling all families with PKU or an Allied Disorder!
We want to know how you handle your disorder!**

We are looking for short 2-3 minute video submissions on how you handle the your or your child's disorder.

These videos will be charged at our 2015 PKU Organization of Illinois Meeting

We are looking for a minimum of one video per each age group:

- **Miracle of New Born Screening**
- **Newborn**
- **Toddler**
- **Early Childhood**
- **Elementary**
- **Middle School**
- **High School**
- **College**
- **Adult**
- **Pregnancy**





WE NEED YOU TO VOLUNTEER!

POSITIONS INCLUDE

- VICE PRESIDENT
- TREASURER
- SECRETARY
- PKU PRESS EDITOR
- NPKUA REPRESENTATIVE
- CAMP DIRECTOR (2)
 - FOOD COORDINATOR (2)
 - ACTIVITY COORDINATOR (2)
 - CAMP VOLUNTEERS –
MULTIPLE

SUBMIT YOUR LETTER OF
INTEREST TO:

PKUILLINOIS@GMAIL.COM



WHAT DOES THE JOB ENTAIL?

All board members must attend monthly meetings either in person, or by phone!
All board members must attend various Board sponsored events and assist where needed!

VICE PRESIDENT

- Coordinate Family Fund Day
 - Zoo contract
 - Coordinate catering
 - Coordinate LP food donations
 - Write follow up article for PKU Press
- Assist President in Coordinating the Annual Meeting
 - Help secure Annual Meeting Location
 - Coordinate Catering

TREASURER

- QuickBooks experience suggested, but not necessary
- Make bank deposits
- File Taxes for the Organization
- Coordinate Wine Tasting & Silent Auction Event
 - Find and Book event location
 - Coordinate Food (Low Protein food required)
 - Coordinate LP Food Donation
 - Solicit for donations starting in early spring
 - Write follow up article for PKU Press
- Position requires 5-10 hours a month

SECRETARY

- Set meeting dates at first meeting
- Reserve venue for meetings.
- Set agenda for meetings and take notes
- Order food in advance for meeting.
- Send meeting minutes to board
- Write thank you letters to people/businesses who give grants, support to our events
- Check board emails and voicemails. Reply promptly
 - Forward emails to appropriate people

- Plan Parent Café once a year
 - Find and book event location
 - Prepare educational materials
 - Prepare snacks
 - Contact clinic reps to help with event
 - Write follow up article for PKU Press
- Position requires 2-5 hours a month on average

PKU PRESS EDITOR

- Microsoft Publisher or Adobe InDesign experience suggested, but not necessary
- Create high quality flyers for each event
- Create engaging layouts for each PKU Press
- Create Save-the-Date Flyer and Annual Meeting Brochure
- Create Save-the-Date flyer and Camp Brochure
- Follow up with all board members for event information
- Contact clinics for clinic updates and Ask PheBea
- Contact Vendors for events and product updates
- Contact Allied Disorder Groups for updates or Feature an Allied Disorder in-depth
- Forward event flyers and information to Website and Social Media Administrators
- Seek community members willing to write articles about their experiences with PKU or an Allied Disorder
- Help vendors coordinate Low Protein Cooking Classes
 - *Duties involved will depend on vendor
- Position requires 12-15 hours a month



NPKUA REPRESENTATIVE

- Attend 5 meeting per year via phone and one meeting in person per year
- Participate in one committee
- 100% Board Giving – give what you can individually on an annual basis
- Email votes/requests
- Actively participate and help represent the diverse voices in the PKU community
- Give updates during PKU IL board meetings
- Write article for PKU Press on NPKUA Lobby Day or NPKUA Conference

CAMP DIRECTOR

- Set schedule of meetings for camp subcommittee
- Find and secure event location
- Set start and end time of camp
- Create camp proposal to present to board (Camp Proposal is due by February 28th)
- Oversee subcommittee and help where needed
- Track registration and answer inquires about camp
- Relay menus, schedule, activities, maps and other pertinent information to camp attendee's.
- Cabin Assignments
- Assign price for each family to attend camp
- Write follow up article for PKU Press

-FOOD COORDINATOR

- Coordinate with Camp Directors
- Plan menus for camp
- Create grocery list
- Contact LP food vendors for food donations
- Obtain food for camp
- Have volunteers lined up to help with cooking and serving
- relay information about what is available or needed for formula storage

-ACTIVITY COORDINATOR

- Coordinate with Camp Directors
- Plan activities, crafts, games, rentals and Prizes
- Acquire necessary items for activities, crafts, games, and prizes.
- Put together schedule of events
- Coordinate volunteers for each specific event

-CAMP VOLUNTEERS

- Assist Camp Director's and Food and Activity Coordinators



C O O K I E

E X C H A N G E



I can't believe the time is here.
To swap our cookies again this year.
It's time to search your receipt book, for the perfect cookie
in taste and look.
Some will have raisins, or chips.
Some with frosting that sticks to your lips.
Crunchy or gooey, melt in your mouth, something decadent
from the south.
Giant, or bite sized to fit in your hand.
Covered with glaze or sugary sand.
There is flour from your head to the floor, as you bake 6
batches you need one more.
Finally you're finished and as you stand back,
You look at your cookies they're great that's a fact.
After we swap and someone has won, the outcome won't
matter everyone had fun.
Remember our goal yes that's right.
Friends and cookies on a December night.

Saturday, December 12th, 2015

2:00pm—4:00pm

342 Sparrow Lane
Bartlett, IL 60103

Hosted by:
Linda & Pamela Kowalczyk

RSVP at PKUIL.org by:
Friday, December 4th

Please bring 2 dozen low protein
cookies, candies, or dessert bars
for the swap as well as copies of
the recipes to share with other
families!



Ever wonder where your donations go?

It may also be helpful to know that since 2010, we (the NPKUA) have invested \$1.3 million in research. Some of our initial successes with these funds raised primarily by local organizations have resulted in:

- Accelerating a clinical trial by 3–4 years of hepatocyte liver transplantation in the first U.S. patient as the result of funding two fellows at the University of Pittsburgh
- Research towards the creation of the first human variant of a genetically engineered probiotic at the University of North Texas has been purchased by a biotech firm
- Leveraging NIH funding for gene therapy at Oregon Science and Health University
- Leveraging studies in the mouse model to translational studies in human PKU on skeletal fragility and have resulted in several publications in peer reviewed scientific journals of University of Wisconsin

How much does a does each research grant cost?

- NPKUA grants are \$40k per year per individual
- NPKUA fellowships are \$55k per year
- The NPKUA puts out 6–8 grants and fellowships per year!
- As you can see, research for better treatment and a future cure needs lots of support, your donations matter!

Save the Date!





National
PKU
Alliance

Join Us!

TOGETHER We Can Impact PKU

Membership
that **PAYS** for
itself!

Your membership helps us improve the lives of individuals with PKU, pursue a cure, and saves you money!

YOUR \$30 YEAR INDIVIDUAL/FAMILY MEMBERSHIP INCLUDES:

- \$75 coupon for new members and \$25 for renewals on a Cambrooke Foods order and a chance to win an Ninja Kitchen System Blender
- Online coupon on Facebook/\$.55 coupon toward So Delicious products
- 5% discount on Country Sunrise products at PKU Perspectives
- Low protein gift pack (\$50 value) from Nutricia
- One free product from Lil's Dietary Shop
- Free box of Vitabites from Vitaflo
- Assistance with Medical Foods (Formula) Insurance Denials



MAKE A DONATION!

Your additional donation will support the four program areas of the NPKUA:

Research, advocacy, education, and support. Help the NPKUA change the future of PKU!

Join today online at www.npkua.org or return the slip below to us at NPKUA, PO Box 501, Tomahawk, WI 54487. If you have additional questions about Membership please contact Katrina Swenson at 715-437-0478.

CONNECT WITH US: DONATE, BECOME A MEMBER

Name _____ Relation to PKU _____

Address _____

City/State/Zip _____

Phone: Cell Home _____ Email _____

Individual/Family Membership (\$30) Optional Donation \$ _____ Total\$ _____

Please charge \$ _____ to our: Visa MasterCard Discover American Express
Number _____ Exp. ____/____ Security Code _____

My check for \$ _____ is enclosed. (Please make check out to NPKUA.)

National PKU Alliance | PO Box 501 | Tomahawk, WI 54487 | www.npkua.org



UIC Chicago Clinic Staff

Updates from the Clinics



Dr. Jones

University of Illinois Chicago

The University of Illinois Genetics and Metabolic clinic continues to see patients at several locations including in Chicago, Rockford, Oak Lawn, Naperville, Springfield, and Peoria. Our clinic staff includes physicians, Dr. George Hoganson and Dr. Zohra Shad. Dietitians include Lauren Dwyer, Amanda Nelson, Shannon O'Brien, Terri Hudson, and Diane Simon at our Rockford location. Genetic counselors include Rich Dineen, Annie McRae, Jennifer Burton at our Peoria Location, Sid Zell and Jessie Nicoll at Oak Lawn, Susie Stillwell and Gina Morley at Rockford. Our clinic coordinator is Jaime Thomas. We were excited to welcome Shannon and Terri over the past year as our newest dietitians. Please see their bios below. We continue to be involved with the Inborn Errors Metabolism Collaborative study.

Shannon O'Brien, MS RD LDN

Becoming an RD was a second career decision for me. When my youngest of four children started preschool, I returned to graduate school to pursue a Master's Degree in Nutrition. I

knew I wanted to focus on pediatric nutrition and, early on, was fortunate to find a position as a grad student in the department of Pediatric Genetics at UIC. I really enjoyed this niche of nutrition and was delighted to eventually turn my years of experience into a part-time position. When not at work, I am often on the sidelines of my children's sporting events or, of course, trying to get that nutritious dinner on the table for my family!

Terri Hudson, MS RD LDN

After receiving my masters in nutrition and dietetics from UIC, I joined the team in January. Through my dietetic internship, I had rotated with the UIC team while in school. After my experience, I knew I wanted to be a part of this community. I am very thankful to now be serving such wonderful patients and devoted parents. Prior to becoming a dietitian, I worked as a pediatric nurse in oncology/hematology and rheumatology. I am a Chicago native, born and raised in the Windy City. Recently, I transplanted to the suburbs with my husband. We are looking forward to becoming a family of three and wel-

coming our daughter in October.

Rush University

The Rush University Medical Center Section of Genetics is pleased to welcome Dr. Carolyn Jones, MD, PhD, and Sara Cherny, MS, CGC to their team. Both are excited to be members of the Rush medical community.

Carolyn Jones, MD PhD

Dr. Jones is the new Section Director, and has over 15 years of experience in the field of genetics. She obtained her medical degree from Rush Medical College, completed residency at University of Chicago Children's Hospital, and completed a Clinical Genetics Fellowship at Advocate Lutheran General Hospital.

Sara Cherny, MS CGC

Sara Cherny is a genetic counselor with over 8 years of clinical experience, who has a Master's in Cellular and Molecular Biology and Genetics from the University of Minnesota.



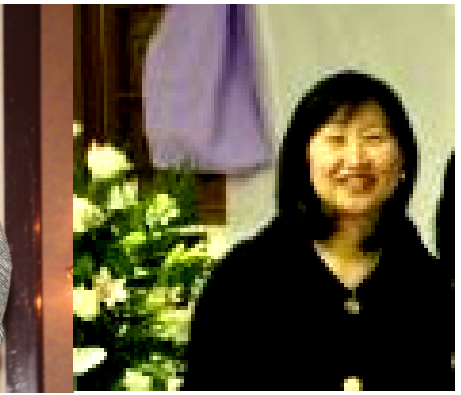
Sara Cherny, MS CGC



Alexa Hart, MS CGC



Dr. Barbra Burton MD



Soo Shim, MS LCSW

Alexa Hart, MS, CGC

They join Alexa Hart, MS, CGC, who has been the prenatal genetic counselor at Rush for 3 years. Alexa received her Master's in Genetic Counseling from Northwestern University. She is available to meet with patients or families to discuss genetic issues related to pregnancy or family planning.

Lurie Children's of Chicago

At Lurie Children's we continue to see patients at our Chicago location every Wednesday and at our Westchester locations every third Wednesday of the month.

Dr. Barbra Burton MD (clinic director, metabolic geneticist), Andrea Paras MS (Clinic coordinator, genetic counselor), Angela Dean (Administrative assistant, receives phe levels), Rachel Katz MS, LSW (Research Coordinator), and Heather Bausell RD, LD (Metabolic Dietician) have recently welcomed three new addition to their staff. Please welcome Social Worker, Soo Shim, MS, LCSW and Metabolic Dieticians, Katie

Arduini RD, LDN, and Amanda Aspan MS RD LDN to our staff.

We continue to recruit subjects at least 18 years of age into the Phase 3 study of the investigational drug Pegvaliase (formerly referred to as PEG-PAL) sponsored by BioMarin. It is likely that recruitment will cease within the next several months when the targeted enrollment has been reached. At that time, all enrolled subjects will be followed until the study is completed at which time the data will be analyzed and submitted to the FDA.

We also continue to follow younger children enrolled in PKU-015, the study of the safety and efficacy of Kuvan in patients under six years of age, including subjects enrolled in the first year of life. Data from the first two years of the study have been published and show that the drug is safe in young children and works in the same way as it does in older individuals. Children will be monitored in the study for a total of 7 years

demonstrate that cognitive function is preserved in treated patients.

We also have many patients enrolled in the registry referred to as PKU-DOS. This is a study that involves only entering information gathered during the course of routine PKU care into a central registry where it is combined anonymously with data from other clinics. There are over 1000 patients nationally in the registry, which is giving us important information about the long term effects of PKU on patients, as well as answering specific questions such as those related to the safety and efficacy of Kuvan during pregnancy.

A huge thank you to the clinics. We would like to applaud you for the endless support, counseling, and efforts in finding a cure!

From the PKU Organization of Illinois and its members.

Dear Phebea-

Why are Tyrosine levels important?

Dear Phebea,

When I go to the doctor they often check my phenylalanine level, but they also check another level called tyrosine. I'm not really sure what tyrosine is and why they care about the level, can you help explain it?

-Baffled by my blood levels

Dear Baffled by my Blood levels,

I'm so glad you asked about your tyrosine level! It can often be confusing when your doctor tells you a level for something like your tyrosine, and you don't really know what it means. I'm happy to help explain why your clinic would care to check your tyrosine level, and why tyrosine is important.

Tyrosine is an amino acid like phenylalanine; it is a building block of protein. Typically when we consume protein, phenylalanine is broken down and converted to tyrosine by the enzyme phenylalanine hydroxylase (PAH). When you have phenylketonuria (PKU), your PAH enzyme is either absent or very low, which means you are unable to convert phenylalanine to tyrosine. So we have to find ways to ensure that you can get tyrosine into your body because tyrosine is essential for your growth and development. Tyrosine play many important roles in your body. It is a building block for several important brain chemicals called neurotransmitters, including epinephrine, norepinephrine, and dopamine. Neurotransmitters help nerve cells communicate and influence mood. Tyrosine also helps produce melanin, the pigment responsible for hair and skin color. Tyrosine helps in the function of organs responsible for making and regulating hormones, including the adrenal, thyroid, and pituitary glands. It is involved in the structure of almost every protein in the body ¹.

Medical formulas for PKU are highly supplemented with tyrosine. The companies that make your formula understand how important it is that you get it in your diet.

Foods that are high in tyrosine are high in protein which is a challenge for people with PKU. This is why we supplement formula to get tyrosine in your diet. This is another reason as well why drinking your formula regularly is healthy for you.

Keep in mind that tyrosine does not mix well into solution. When you mix your medical formula and you find settlements at the bottom of your cup/shaker, that is often the tyrosine that is important for you. Remember to shake up your formula before drinking to ensure that you get all of the tyrosine from your formula.

Your tyrosine levels are often checked at clinic to ensure you are getting enough tyrosine. As you can see tyrosine is important for your health. It can help with your brain functioning, mood, hair and skin coloring and helping to maintain brain and body functioning. If you have not been taking your formula regularly, you can ask your doctor to check your tyrosine level. You can also consider different medical formulas that may have higher levels of tyrosine.

I hope this helps explain tyrosine a little! Ask your clinic, doctor or dietitian if you have other questions or concerns!

Sincerely,

Phebea

Reference

<http://umm.edu/health/medical/altmed/supplement/tyrosine#ixzz3domLF53b>

Stay Connected!

Email or mail us your....

*Name: (First and Last) : _____

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Email: PKUillinois@gmail.com

Website: www.PKUIL.org

August

Lil's Dietary Specialty
2738 W. 111th Street
Chicago, Illinois 60655

Thursday, August 20, 2015
6:30-8pm

Questions:
metabolicdieticians@luriechildrens.org

September

CamBrooke Low Protein Workshop
From the Field Cooking School
2029 S. Main Street
Morton, Illinois 61550

Saturday, September 19, 2015
9:30- 1pm

Register at:
www.PKUIL.org

October

Wine Tasting & Silent Auction
Letizia's Fiore Ristorante
2456 North California Avenue
Chicago, Illinois 60647

Saturday, October 3, 2015
5:00-9pm

Register at:
www.PKUIL.org

November

PKU Annual Meeting
Skokie Holiday Inn
5300 W. Touhy Avenue,
Skokie, Illinois 60077

Saturday, November 7, 2015

Register at:
www.PKUIL.org

December

Cookie Exchange
Linda Kowalczyk Home
342 Sparrow Lane
Bartlett, Illinois 60103

Saturday, December 12, 2015
2:00-6:00pm

Have a Happy New Year!
We will see you in 2016!!!