



Fall

2016 PKU Press



Event Recaps



Clinic Updates

Dear Phebea-

Carlos R. Galvez Memorial Golf Tournament

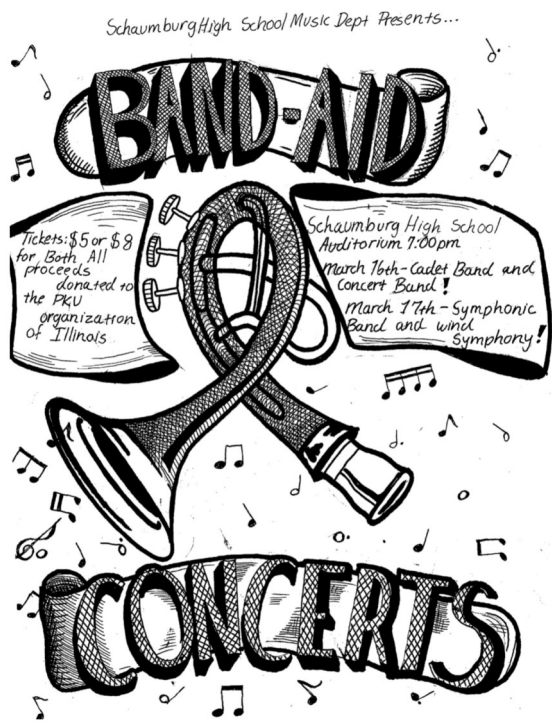
Wine Tasting & Silent Auction

Annual Meeting Save the Date

Now Seeking

New Board Members

COOKIE
EXCHANGE



March 16 and 17, the Schaumburg High School Cadet Band, Concert Band, Symphonic Band and Wind Symphony put on their annual Band Aid Concerts. Every year the Schaumburg High School Music Department selects a different cause to support and help to raise awareness and funds for. This year they choose the PKU Organization of Illinois. They invited the President of the Organization, Danae' Bartke to come speak on behalf of the PKU community. There, she was able to speak to the audience members about what PKU is and how impacts the lives of the patients and their families. All proceeds

from the concert were donated to the organization. The Band Aid Concerts brought in a little over \$2,000 for the organization!



Ashleigh Ginter

Ashleigh Ginter, a junior at Schaumburg High School has PKU and suggested the PKU Organization of Illinois support for their 2015-2016 Band-Aid Concert series. Ashleigh is an accomplished flute and Piccolo player in the Symphonic Band. She too was able to share her experience with what it is like to have PKU and tell her personal story. Thank you Ashleigh and the Schaumburg High School Bands for providing us with this opportunity!



Schaumburg High School Bands



Recap, Family Fund Day 2016.

Saturday, May 14 we gathered at Blackberry Farms for our Annual Family Fund Day. All profits from this event were donated to the National PKU Alliance to help with research for a cure! Despite the frigid temperatures, the day was a success! Over 80 people came out, to help us raise approximately \$5,000!

Registration started at 10 am. Once registered families were able to visit the vendors, and walk the farm. The kids loved the various activities the venue had to offer. The train rides, carousel rides, pony rides, petting zoo, and more kept everyone busy until lunch. Lunch this year was graciously cooked by two of our board members, Danae' Bartke and Dean Seppelfrick. It in-

cluded low protein pulled jackfruit, regular pulled pork, various, picnic salads, and low protein cupcakes for dessert! We finished the day with our 50/50 raffle, and a group picture. As you can see we had a wonderful time!

BD's Mongolian Grill Fundraiser

Did you go Mongo for PKU? On Thursday, June 16 approximately 53 people came out in support to BD's Mongolian Grill in Naperville to help support the PKU Organization of IL. For every table that mentioned the organization, 3 dollars from each person at the table was donated to the organization. Between those who came out to support us and tips, we were able to raise \$200! Families enjoyed food that could be easily adapted to the low protein diet

Board members, Dean, Kim, and Pam cooking up some of the fair!

Some smiling faces enjoying the train at Blackberry Farms



Parent Café Follow up

We had a great time meeting parents and grandparents that attended this year's New Parent Café in Lisle in June. More than 10 families with children ranging from 8 months to 10 years were able to share stories, tips, tricks and meal ideas. We are so grateful to our vendors for their active participation in the PKUII community - Nutricia Metabolics, BioMarin, Cambrooke Therapeutics, POA Pharmaceuticals and Vitaflo had tables and/or samples available to share their information with parents for their products, and a full spread of breakfast options (and on-demand waffle bar!) provided by Cambrooke food and recipes from CookForLove.org for all to enjoy.

Each guest also was able to leave with a "goodie bag" and folder full of samples, recipes, information and tools for everyday PKU life thanks to these amazing companies and the PKUII board members! We also extend our sincere gratitude to the metabolic teams at UIC and Lurie's for taking the time to attend and answering questions - their constant support for our organization is overwhelming. We hope to see you at next year's event!

Jordan Franks . (1/28/00 – 6/26/2016)

Death Notice

It is with a heavy heart we announce the passing of fellow allied disorder member Jordan Franks. Jordan Franks, 16 was the inspiration for the founding of the Propionic Acedima Foundation. His mother, Jill Franks served on the PKU Organization board and worked tirelessly for the inclusion of the Allied Disorders into the organization. Franks, also went on to be the founder of the Propionic Acidemia Foundation. The board has made a donation in his name to the Propionic Acidemia Foundation. You can leave your condolences at: <http://tinyurl.com/zb4kl36>. You can also leave a donation in memory of Jordan at: www.pafoundation.com

You're Invited!

Join us for an interactive, PKU cooking class

Join Chef Jeff Masse for a day of hands-on cooking the low-protein way! You will take away useful cooking and nutritional tips, as well as a variety of easy and delicious recipes for all members of the family to enjoy. At the end of the event, enjoy the recipes prepared that day!

Hear Ashley Vollenweider, MSN, CPNP, of the University of Utah, speak about "PKU and You: Advocating for Excellent Care."

WHEN:

Saturday, August 13, 2016
10:00 AM-2:00 PM
Low-Phe Meal will be provided

Register Now

Space is limited!
To reserve your space visit
www.pkuevent.com/chi

WHERE:

The Chopping Block
222 West Merchandise Mart Plaza #107
Chicago, IL 60654

Or call 855-PKU-CALL
(855-758-2255)

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

Limit of three family members or friends per each person with PKU. This event is for families with children 4 and up. Childcare will not be provided during this event.

Free parking vouchers provided for Mart Parc Wells garage, 401 N. Wells (caddy corner North and East, across the street from Merchandise Mart).

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



BioMARIN

PKU.com

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You're Invited

Join us for an interactive, PKU cooking class

Join Chef Jeff Masse for a day of hands-on cooking the low-protein way! You will take away useful cooking and nutritional tips, as well as a variety of easy and delicious recipes for all members of the family to enjoy. At the end of the event, enjoy the recipes prepared that day!

Hear Laura Jeffers, MEd, RD, LD, of the Cleveland Clinic, speak about "PKU Treatment Adherence Through Life Transitions."

WHEN:

Saturday, September 17, 2016
10:00 AM-2:00 PM
Low-Phe Meal will be provided

Register Now

Space is limited!
To reserve your space
call 855-PKU-CALL
(855-758-2255) or visit

www.pkuevent.com/nap

WHERE:

Sur la Table
55 S Main St
Naperville, IL 60540

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

Limit of three family members per each person with PKU. This event is designed for families with children ages 8 and up. Childcare will be provided during this event.

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



BioMARIN

PKU.com

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USPKU0671EN-NOV2014

Important:

Must be given to only PKU patients under strict medical supervision. Dosage to be determined by the clinician or dietitian. Not for use as a sole source of nutrition. Not for parenteral use.

Storage:

Store in a cool, dry place.

Marketed and Distributed by:



4400 NE 77th Avenue
Suite #275
Vancouver, WA 98662
T: (855) 416-6826
F: (360) 326-1621



Request samples by email

sales@POAPharmaNA.com



PKU Easy Microtabs:

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

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

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

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

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



PKU Shake & Go:

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

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

Just add 3-4 ounces of cold water to the bottle, shake, and enjoy. PKU Shake & Go is convenient and makes traveling a breeze.

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



September 23-25, 2016

East Bay Camp

24248 Ron Smith Memorial Hwy. Hudson, Illinois 61748



Space is limited!

Register now at PKUIL.org!

**Deadline to register:
September 14**

Arts and Crafts

Relay Races

Yard Games

Nature Hike

After Dark Games

Indoor Swimming!

Hay Ride

Fishing Contest

Bonfire

Camp Fire Songs

PKU S'mores

Health Activities

Make your own Trail mix

Campfire Cooking

And more!

FAMILY CAMP

The title 'FAMILY CAMP' is rendered in large, colorful, 3D-style letters. 'FAMILY' is in green and 'CAMP' is in red. A yellow tent is positioned behind the 'A' and 'M' of 'CAMP'. A small blue bird is perched on the top of the 'Y'. The entire graphic is set against a light blue background with a white outline.

Friday	Saturday cont.	Sunday
5:00-6:00 p.m. Sign in, unpack, get to know each other.	10:30-11:30 a.m. Arts and Crafts	8:00-9:00 a.m. Breakfast Provided by campers
6:00-7:00 p.m. Dinner—Walking Tacos	11:30-12:30 noon Pasta with Marinara, Focaccia, “meatballs” salad and fruit	9:00-9:30 a.m. Nature Hike
7:00-8:00 p.m. Rules and Getting to know you activity	12:30–1:15 p.m. PKU Educational Activity	9:30-10:15 a.m. PKU Educational Activity
8:00– 9:30 Bonfire and S'mores	1:15-2:15 p.m. Swim/Open Gym	10:15-10:30 a.m. PKU Camp Picture
Saturday	2:15-5:15 p.m. Teams Course and Yard Games	10:30-11:45 a.m. Pack up– Clean up! Everyone helps!
7:30–8:30 a.m. Breakfast Waffles with butter and Syrup.	5:1105-6:30 p.m. Campfire Dinner Hobo Stew/ Veggie Kabobs Fruit salad, orange campfire cakes	12 noon Good Byes! Check out
8:30-8:45 a.m. Review Agreements Overview of Schedule	6:30-7:00 Hayride	
8:45-10:00 a.m. Fishing Derby Prizes will be awarded	7:00-7:45 Restorative Circles	
10:00-10:30 a.m. Nature Scavenger Hunt	8:00 –10 Campfire After Dark Games!	

Carlos R. Galvez
Memorial

GOLF Tournament

Sunday, October 9, 2016

Broken Arrow Golf Club
16325 W. Broken Arrow Dr.
Lockport, Illinois

8:00 am Registration
9:30 Shotgun start

Cost: \$100.00
Includes: Green fee, cart,
Snack, dinner, door prizes,
Trophies, hole-in-one
Prize and many more!

Sponsored by :
Tamaraw Golf Club

To benefit:
PKU Organization of
Illinois

To participate or donate call or email: Bay Galvez
Cell: 708-624-0113 & baygalvez@aol.com



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your Insurance Plan?

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TO LEND A
HELPING HAND



Talk to a Nutricia
Reimbursement Specialist

800-605-0410

Coverage@Nutricia.com

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 PKUILL.org

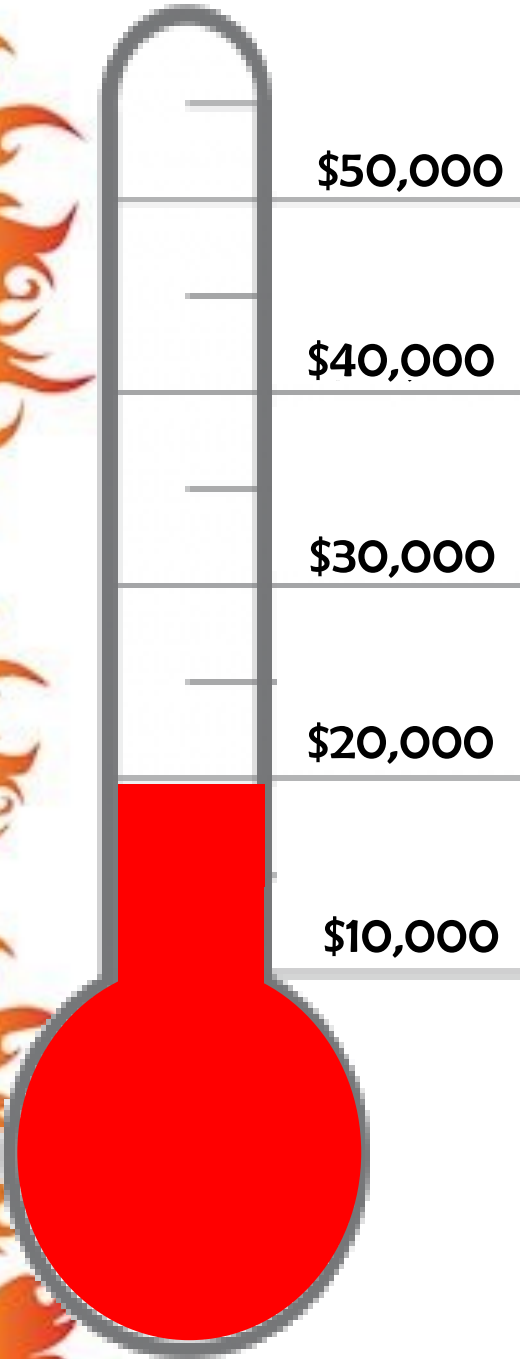
Monetary donations and auction items are greatly appreciated!
Please email us at the address below if you have auction to donate!

Questions? pkuillinois@gmail.com



Help Spike the PHEver for a Cure

\$50,000



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

\$20,00 Operating Cost

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 Guthrie
\$5,000

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



Looking to the Future!

Novel therapeutic approaches for inborn errors of metabolism

Keynote Speaker: Dr. Olaf Bodamer

Boston Children's Hospital & Harvard Medical School

**2016 PKU Organization of Illinois Annual Meeting
Saturday, November 12, 2016**

Hilton Oakbrook Hills Conference Center

3500 Midwest Rd, Oak Brook, IL 60523

Book your room today! 630-850-5555

(Don't forget to mention PKU Organization of Illinois)



The last years have seen an unprecedented number of new therapies for genetic disorders including inborn errors of metabolism (IEM). These therapies either target the underlying genetic defect (curative approach) or the metabolic consequences (symptomatic approach) with the goal to prevent or limit disease related complications and to improve overall quality of life.

Curative approaches include 1) gene therapy 2) bone marrow, liver and stem cell transplantation/therapy 3) read-through pharmacological therapies.

Disorders of protein metabolism are amenable to therapies that increase activity of the missing enzyme through different mechanisms. One such example is subcutaneous PEG-PAL that has led to a significant decrease in blood phenylalanine levels in individuals with PKU in phase 2 and 3 trials. Similar therapies are currently in pre-clinical development for HCU.

The lecture will provide an overview of the latest therapeutic developments for IEM with a particular focus on PKU, HCU and MSUD.

**Special Guest Chef, Brenda Winiarski-
Founder and Operator of:**



New Panel Style Discussion –
Audience members will be able to ask clinical and patient experts questions

Already have a question for the panel?
Email us at: pkullinois@gmail.com

Children's program available for ages 6-12

Attention

PKU and Allied Disorder Community!

We are now seeking new board members

- Treasurer
- PKU Press Editor
- Camp Director
- At large board members

Contact pkullinois@gmail.com for more Information, or if interested.



NUTRITION YOU NEED FOR THE LIFE YOU LIVE.



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UNIVERSITY OF ILLINOIS
Hospital & Health Sciences System
Changing medicine. For good.

Updates from the Clinics

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

All, for your one.

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, Peoria. And Springfield. We know our patients travel far to see us, and we do our best to make efforts to get to convenient locations as well. Our physicians are Dr. George Hoganson, Dr. Zohra Shad, and Dr. Gifty Bhat. Dietitians include Lauren Dwyer, Shannon O'Brien, Terri Hudson, and Diane Simon at our Rockford location. Genetic counselors in Chicago include Rich Dineen, Maria-Renee Coldagelli and Elizabeth Kaplan. Jennifer Burton is at our Peoria Location, Jessie Nicoll is at Oak Lawn Christ location, and Susie Stillwell and Gina Morley are at Rockford. Our clinic coordinator is Olivia Villarreal. We were excited to welcome some new team members and expand our staff this year. We were excited to welcome Dr. Bhat, Maria-Renee, Elizabeth and Olivia to our team this year!

Lurie Children's Hospital

As individuals with Phenylketonuria (PKU) become older, an increasing number experience difficulty maintaining consistent PKU management. In light of the challenges adults face, the PKU team of Ann & Robert H. Lurie Children's Hospital of Chicago implemented the PKU Adult Boot Camp. The goal was to offer an educational opportunity for adults with PKU outside of a routine clinic appointment to further emphasize the importance of treatment adherence and to build upon skills to effectively manage PKU.

We designed the PKU Boot Camp with the mindset of targeting adults 18 years of age and older who were interested in returning to treatment

and or were on treatment but would like to improve their management. The boot camp was a four week program. Each week we obtained phenylalanine (phe) levels and diet records from each participant to determine treatment progress. The participants were given small "homework" assignments to encourage them to think about the topics presented during the week. Social interaction and connection was emphasized throughout boot camp and included group correspondence through e-mail, individual and group participation, and discussions regarding overcoming treatment barriers.

The weekly education sessions focused on a variety of topics including an overview of PKU, genetic inheritance, tips for counting phe and protein, meal planning, navigating insurance and the importance of medical formula. A low protein meal was provided at each session and recipes were provided to encourage the participants to try to cook these meals at home. We also incorporated taste

tests of several medical formulas and low-protein foods. Two of the boot camp participants had the opportunity to share their successes in PKU management. The final session we encouraged participants to bring in a favorite low-protein food to share with the rest of the group. Boot camp concluded with a graduation ceremony during which each participant received a certificate of completion and a PKU Boot Camp t-shirt.

The PKU Boot Camp was a very successful program. A total of eleven adult patients and five support individuals participated in this program. Participants were encouraged to bring a supportive individual to each weekly session. As a clinic, we hope to organize future Boot Camp programs as well as other group classes targeting other populations. This educational series enriched our awareness of the PKU adult population and we look forward to creating future opportunities that will continue to be helpful for the PKU patients, their support systems, and the PKU clinic staff.



Members of the PKU Community at the Lurie's Boot Camp.

Dear Phebea,

Preparing for back to school

Dear Phebea,

I need some good back to school tips! What are the best things to do to prep for school?

Sincerely,
Learning Lucy

Hi Learning Lucy,

There are lots of things to think about in regards to managing a PKU/low protein diet and heading to school for the first time or just back to school.

Talk to your school and teachers. It's really helpful to talk to the school to inform them about your condition. Some people have a 504 plan in place, which will help with their specific diet. Clinics can help provide a letter of explanation if necessary.

Have a formula/ 'milk' plan. It is recommend to take formula throughout the day, so a lot of people will talk with the school/teachers or the school nurse about times that would work to take formula during the day. Some families and patients consider a different formula that is already pre-mixed that is easier to take to school each day.

Menu planning. Take a look at the school's lunch menu

and decide if there are options to choose from on the school lunch that you can combine with low protein options, or come up with a rotational meal plan of lunches you can take from home that could be easy to implement. It's helpful to have treats on hand that are low protein friendly in case of any special treats that may be served.

Seek out resources. Remember to advocate for yourself or your child. IEP (Individualized Educational Plans) can be helpful to get assistance in areas that are needed. Also talking with anyone such as teachers, administrators, or clinic team members is a helpful way to identify other areas that you need to consider, and also other areas that you could get assistance with in managing PKU or allied health condition.

Have a brief explanation. Some people don't mind talking about PKU or other condition, but other people feel private. Have a brief concise explanation that you could say if other students or teachers ask you questions.

Reassess. Touch base with the school or teacher after the first month or so of school to see how things are going. This is helpful to identify if changes need to be made or not.

I wish you the best of luck in school this year!
Phebea

Did you know PKU gel can help your child reach feeding milestones?

- Concentrated second stage medical food
- Designed to decrease reliance on high volume formula
- Promote appetite for food
- Has a consistency that may better suit feeding development

For more information or to request a sample,
visit www.VitafloUSA.com

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**Join us for a jolly good time
At the Kowalczyk's
Cookie Exchange**

**Saturday, December 10, 2016
2:00-4:00 pm
342 Sparrow Lane,
Bartlett, Illinois 60103**

**RSVP by and at:
Friday, December 2nd
Pkul.org**

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

Letter Regarding the Future of the PKU Press

Dear Pku and Allied Disorder Community,

Over the past few years, our donations have decreased and due to budget cuts we will be discontinuing to print the PKU Press for free. Please be aware you will still be able to access the PKU Press online and will also be sent out via Constant Contact. If you wish to get a free electronic version of the PKU PRESS, please make sure you either subscribe to our constant contact list, or by checking our website in April and August for it's release. If you wish to still get a printed copy in full color, please send in \$10 for a year long subscription to the address listed below. Please note on the memo it is for the 2017 PKU Press subscription. We will also include a envelope in the Annual Meeting flyer to subscribe.

Thank you for the understanding and continued support.

Danae' Bartke,
President, PKU Organization of Illinois

Stay Connected!



PKU Organization of Illinois



@pkuillinois

Email: PKUillinois@gmail.com

Website: www.PKUIL.org