



**PKU Organization
of Illinois**
P.O Box 102
Palatine, Illinois
60078-0102

PKU Organization of Illinois- Board Meeting

DATE: June 29, 2016

TIME: 7:00 p.m.

LOCATION: Call in

Call in Info: (630) 874-7007 Pass code: 12041

Meeting Agenda

6/29/2016

I. Roll Call:

Not in Attendance

On the phone:

Danae' Bartke

Matt Bartke

Mary Lonski

Joe Bonucci

Dean Seppelfrick

Andrea Hall

Grant Smith

Pam

Ben

Kim

Hazel Vespa

Soo Shim

II. Officer Reports

- A. President's Report –**
\$500 to be donated to Propronc Acidemia foundation on behalf of Jordan Franks passing.

Andrea will mail it out.

Maybe we can set up a fund to donate to allied disorders annually.

- B. Vice-President's Report- Grant – Raffle Tickets:** not looking promising. Will keep investigating.

- C. Treasurer's Report-** Andrea – P&L to date.

- D. Secretary's Report-** Matt – Grant brought it to the table, everyone approved.

- E. NPKUA Update – Kim –**
July conference has over 500 attendees. They are reviewing the presentations.

NPKUA is working with BioMarin and to create a patient registry.

Also working with various vendors to identify patients who are not on diet, and help get them back on diet.

III. Committees 2015 –

- A. Hospitality Committee**

Family Camp – September 23-25, 2016, East Bay Camp
24248 Ron Smith Memorial Hwy, Hudson, Illinois East Bay Camp
Friday, Sept. 23 check in at 5:00 pm – Sunday, Sept. 25 check out at noon

Pam & Ben – Camp site, activities – will be what we include for the cost.
-FINAL head count one week prior to the event.

What is the camp capacity? If there is enough space, we can include other states.

Camp includes fishing poles.

No charge for vendors.

Agenda:

We will use the agenda Pam sent out earlier.

Donations:

Food:

Friday:
Dinner – Walking Tacos

Saturday –
Breakfast – Waffles – Low protein and regular
Lunch – Nutricia Pasta w/ Cambrooke focaccia bread and “meatballs”
Dinner – Campfire Dinner –

Sunday:

B. Fundraising Committee -

Mongolian BBQ: \$40 in tips, another \$156. We spent \$17.50 on flyers.
Total made after expenses \$178.50

Schaumburg High School Band Fundraiser : The check came in from
tickets sold \$1919.00 – more money to come from t-shirt sales

Wine event: October 15, 2016 - 2144 W Division St, Chicago, Letizia's
Natural Bakery – **Lets make sure that the chart is up to date!**

Carlos R. Galvez Memorial Golf Tournament: Sunday Oct 2nd Broken
Arrow Golf Club 16325 Broken Arrow Dr., Lockport, IL 60441

-This year we need someone there and speak. Grant will be in attendance.

C. Education Committee:

Scholarships – We are now excepting scholarships – help spread the word!

Cooking classes-

Cambrooke – Did any one attend the one in Chicago?
6 families attended – Lil's Dietary Shoppe

BioMarin – July 9th – Morton, Illinois

Nutrica -

Parent Café-

Grocery Store Tour – Clinic and BioMarin hope to do some this summer!

D. Communications Committee

Fall PKU Press-

Articles/ Flyers for PKU Press

- Schaumburg High School Fundraiser
- Family Fund Day Follow Up

- Parent Café Follow up
- Clinic Follow Ups
- Camp Flyer
- Golf Outing Flyer
- Wine Tasting
- Annual Meeting Flyer
- **Cookie Exchange?**
- Ask Phebea
- Recipes
- **Board Positions** – Who is rolling off in the Fall?
 - **Andrea – (Treasurer) - Rolling off**
 - **Ben/Pam – (Camp Director) -Rolling off**
 - **Katie – Rolling off**
 - **Eric – Rolling off**

Ads for PKU Press

-Ads – Mead Johnson would like to have a ½ page paid ad in the Fall PKU Press!



- POA is interested in full size ad.
- Nutricia interested in ½ page ad.

IV. ANNUAL MEETING! - November 12, 2016 - Oak Brook, Hilton Conference Center

a. Dr. Olaf Bodamer - Novel therapeutic approaches for inborn errors of metabolism including phenylketonuria, homocystinuria and others.

- **Looking to the future...**

b. Cooking Demo. – Brenda from Cook for Love!!!

c. Panel style discussion

Panel Idea:

Who will our experts be?

Grant – Moderator

- Dr. Burton
- Dr. Hoganson
- Dietician
- Social Worker
- Jr. High - Gallagher
- High School/College – Sarah Tomkins
- Maternal – Heather Ricca
- Allied Disorder

-Topics we should make sure they can cover?

