



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

PKU Organization of Illinois- Board Meeting  
DATE: February 17, 2016  
TIME: 7:00 p.m.  
LOCATION: Arlington Heights Library

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

## Meeting Agenda

2/17/16

### I. Roll Call

Danae Bartke  
Matthew Bartke  
Grant Smith  
Pam Kowalyck  
Ben Wagner  
Andrea Hall  
Hazel Vespa (call in)  
Mary Lonski (call in)  
Soo Shim (call in)  
Dean Seppelfrick (call in)

### II. Officer Reports

#### A. President's Report – Danae' –

- All board positions are filled
- Revisiting by laws – attendance rules
- Money Collected at each event – You have one week after an event to deposit all monies collected at each event. If you are unable to deposit it, please give the money to Andrea or Danae' to deposit.
- We have new NPKUA Rep. Kim Kowalyck.
- Jeanette Amaya left the board.

#### B. Vice-President's Report- Grant

Nothing to report. Thank you for your time.

#### C. Treasurer's Report- Andrea – 2015 P & L, 2016 Budget Last year net -\$952.

What are our financial goals for 2016? Not be negative. Budget at surplus of \$1000.  
Goals are \$30,000 money raised.

Where will the money go...? Cooked for Love and How Much PHE. Donate up to \$10k for NPKUA

**D. Secretary's Report- Matt – Vote on minutes from last month. Minutes for last month were approved.**

**E. NPKUA Update – Vote on Kim Kowalczyk – Welcome her to the board!**

- Danae' will follow up on Home Phe Monitor Device. They're not pursuing home PHE monitors as aggressively because levels fluctuate too much.

**III. Committees 2015 – Everyone should have their venue(s) booked by next meeting – February! Please have venue cost with you.**

**A. Hospitality Committee**

Cooking classes- BioMarin will be sponsoring the cooking classes for 2016. Other vendors will be invited to participate in each cooking class. Michelle from Biomarin is organizing them.

Camp – Pam- Doing it at East Bay in Hudson, IL. Two weekends are available. Sep 9<sup>th</sup>-11<sup>th</sup> or Sep 23<sup>rd</sup>-25<sup>th</sup> available... Cabins and hotels are available. No costs available yet. We budgeted \$2000 for income and \$1500 for expenses. The board decided to schedule Sep. 23<sup>th</sup> through 25<sup>th</sup> for the event.

## **B. Fundraising Committee -**

Schaumburg High School Band Fundraiser – 3/16 & 3/17 – All Proceeds will go to PKU Organization of IL, Tickets are \$8 a person, will also be selling T Shirts.  
More info coming soon.

Family Fun Day – We don't have an update from Grant today. He will be getting information tomorrow and will update us in the future.

Wine event – Andrea: Booked for Sat Oct 15<sup>th</sup>. Letizia's is the venue at their alternate location on W. Division. The new location has more space.

Beer Garden – Dean: Researched and found within 4-6 mile radius 294/88/355 there are 3 microbreweries in that area.

On the Roosevelt Rd. location, the venue is free on Monday or Tuesday night. The beer is \$7 a person. The price is the same on the weekend.

Another place called Emmetts in Downer's Grove... it is 100ft off of the Burlington train line. They are willing to work with us for making PKU-specific food. It is more expensive because they charge for the event. \$15 per person cost. They will have 12 different beers available.

Danae will get proposal for both of them in writing.

Golf Outing – Andrea: Sunday Oct 2<sup>nd</sup>: This year we need someone there and speak. Grant will be in attendance.

Others – Ladies Night Out? 5K? Jump Zone? Grant says the Jump Zone person is still available, but he has no further details yet.

Ladies Night Out: Postponed

5K: Postponed

Grocery Store Tour: Danae will see if anyone has one in the works.

## **C. Education Committee:**

Scholarship- This will be in the PKU Press. Pam will develop a Rubric for scoring the scholarships. Note: Check Google Drive account for Rubric.

Cooking classes- BioMarin will be sponsoring the cooking classes for 2016. Other vendors will be invited to participate

-Rockford (exact place TBD) April 9, 2016

Parent Café- June 11, 9:30-11:30 at Grounds for Hope Café in Lisle. Nutricia going to be providing new parent kits to the families in attendance.

-We will charge vendors a small fee to have a table.

## **D. Communications Committee**

Press to go out- FEBRUARY!

### Articles for PKU Press

-Annual Meeting -Recap

-Fall cooking class- Recap

-Golf Outing -Recap

- Ask PHE-BE (Lauren),

- Special Interest Article – Ruthie, PKU & Ms. Illinois

-Recipes (Eric),

- Dates for upcoming events
- Scholarship follow ups – I have Taylor Hardy, Michelle Brandon, and Garret Austin’s – no Marrison Pratcher.
- scholarship deadline,
- board meeting recap
- meet the 2016 board (brief bio - 3 sentences from new board members).
- Ads – Mead Johnson would like to have a ½ page paid ad in the Fall PKU Press! ☺

-Announcement – this will be the last year we will be printing the PKU Press – we will still offer the PKU Press electronically!

-We could have those who would like a printed version subscribe and pay a fee – there are a few people I’ve spoken to who would prefer this option and are glad to pay. Danae will obtain a price for the next meeting.

#### IV. **ANNUAL MEETING!!!!** \*\*\*\*\* **November 12, 2016**

- a. Topic - Gene Therapy.
- b. Speaker – Dr. Harding out of Oregon. Will also be presenting at the NPKUA Conference.  
Alternate: Dr. Levy Con: we had him within the last 5 years.
- c. Breakout sessions – 6 rooms available. We can do either a breakout or a panel.  
Panel Idea: Insurance Grant: NPKUA organizes web panel. Find out who the speaker is. Hazel: Hospitals might have some people for educating families available.  
Dean: Possibility for resource is someone from a college or university.  
  
Panel Topic: How exercise/sports affects PHE levels...  
Maybe have Maryam from Vitaflo talk about Formula and sports...
- d. Location- Oak Brook Conference Center November 12<sup>th</sup>
- e. Find a new cooking demo person. Brenda from Cook for Love, Fabio from Letizias. Malethy from Taste Connections.  
Dean: Demonstrate the food and then eat it for lunch. Immediate reinforcement.

Vendors – POA, Vitaflo, Biomarin, Nutricia, Mead Johnson has confirmed they will be in attendance!

Considering asking Field Roast and Diaya to attend...

#### V. **PKU NATIONAL CONFERENCE** July 28-31. Kim will be attending. Danae will see if she can attend.