



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

PKU Organization of Illinois- Board Meeting

DATE: May 18, 2016

TIME: 7:00 p.m.

LOCATION: Arlington Heights Public Library

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

## Meeting Agenda

5/18/16

### I. Roll Call

In person

Danae

Matt

Grant

Ben & Pam

### Not in Attendance

Katie

Joe

Dean

On the phone:

Hazel

Kim

Andrea

Soo

Ami

### II. Officer Reports

- A. **President's Report** – Danae' – Danae is in the final stages of planning
- B. **Vice-President's Report-** Grant – Family Fund Day went well. Would like to have Family Fund Day at Blackberry Farm. We raised \$5,035 roughly. We had 81 out of 91 people show up. We sold 22 shirts and multiple keychains and bracelets. We mad \$201 donation in raffle tickets.
- C. **Treasurer's Report-** Andrea – Deposited money from Family Fund Day
  - Updated insurance on the Google Drive
  - Updated tax exempt form on Google Drive
- D. **Secretary's Report-** Matt –  
Minutes approved from last month – Grant brought it to the table, Pam seconded it.
- E. **NPKUA Update** – Kim –  
NPKUA Conference – 526 people registered  
Maternal PKU Mentor Meeting – 10 mentors – will be talking about the program at NPKUA Conference.

Pegvalise Trail – NPKUA requested more federal funding.  
Pegvalise trial survey was only sent to clinics who were participating in the trial.  
-the survey was to help get FDA approval.

Fraternity -PKU Challenge for a week in North Carolina –

Home PHE Monitor – still working on it – may change approach.  
Mevalia by Dr. Schar products are now available in the US!

### **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.

No charge for vendors.

#### Agenda:

See attached camp agenda – anything highlighted is where help is needed.

Pam needs 4 volunteers for 4 different activity stations.  
Needs 2 volunteers to help with PKU educational activities  
-Moon Balloon as an activity

#### Donations:

Prizes for fishing derby

Maybe Don Souhrada can give us some ideas pointers.

#### Food:

-We have 18 boxes of uncooked Spiral pasta from Nutricia we can use for camp!

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 –

**Mongolian BBQ Fundraiser**

June 16 @ 5:00 am - 9:00 pm

- Overview of program
  - We are paid \$3 per person that simply states they're with PKU Illinois fundraiser
  - We are also paid whatever tips are generated at the grill station
- Support needed
  - We need 3-4 "guest grillers" who volunteer to work the grill and grill guest food –Kim, Danae', Dean,
  - **Recipe ideas – we need help! Maybe Eric Sartain has some ideas.**
- Collateral/Supplies
  - Recipe Cards
  - Flyers/Brochures on "What is PKU" and PKU Organization of Illinois (leave around the grill for awareness while waiting for food) including "Tips appreciated! all tips donated for research and cure for PKU"
  - Tablecloth
  - Scales.
  - Flyer to distribute at events, social, email and email to our friends and family

Schaumburg High School Band Fundraiser –

- F.** Family Fun Day – Follow up – Family Fund Day went well. Would like to have Family Fund Day at Blackberry Farm. We raised \$5,035 roughly. We had 81 out of 91 people show up. We sold 22 shirts and multiple keychains and bracelets. We had \$201 donation in raffle tickets.

Wine event - October 15, 2016 - 2144 W Division St, Chicago, Letizia's Natural Bakery – **Checkup- who has what – should have 4 donations per person.**  
**-Price?**

Beer Garden – Dean

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

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

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

**C. Education Committee:**

Scholarship

Rubric – See attachment – **Passed!**

1; How PKU affects you and others

2. success with PKU

3. Challenges with PKU

4. How overcoming challenges with PKU will prepare you as you go through college

5. Your hopes for your future and how you plan to be a contributing member of society.

Cooking classes-

Cambrooke

BioMarin –July 9<sup>th</sup> – Morton, Illinois

Nutricia

## Parent Café-

### **Parent Cafe:**

June 11 @ 9:30 am - 11:30 pm  
Grounds for Hope Café, Lisle, Illinois  
Currently have 17 people registered!

- Agenda:
  - Arrival/Greeting/Mingle 9:30-10:00
  - 10:00 - 10:45 PKU Overview w/Dr. Burton and Dietitian Katherine Arduini - discuss new research, answer any questions (generally very informal)
  - 10:45-11:00 5 minute increments from 3 attending sponsors, "overview" of their company/products/service
  - 11:00 - 11:30 mingle/meet the parents, meet the vendors
- 
- Flyer: Has been sent to clinics, is on the website, and has gone out via constant contact and FB/Twitter
  - Vendor Support: BioMarin, Vitaflo, Nutricia (sponsoring, but not present), POA, Cambrooke (\$500 in vendor sponsorships)
  - Vendor Tables: BioMarin, Nutricia, POA, Cambrooke
    - Thoughts on including a fundraising company (i.e. Thirty One or Tupperware) at a table, featuring PKU Friendly "cute" prints like coolers, cups, etc. that would be willing to sell online and at a table for fundraising?
  - Goodie Bags - Huge support from BioMarin & Nutricia - POA and Vitaflo will provide collateral - current goodie bags include:
    - Nutricia: Low protein flash cards, electronic scales, shakers bottles, measuring cups, recipe book and Low-Pro food samples
    - BioMarin: small tote bags, diet record journals, shakers, measuring cups, measuring spoons and cutting boards
    - POA providing collateral and samples
    - Will be stuffing first week of May – all items are due to Ami by 5/27
  - Checks: receiving vendor checks - can mail them to Andrea - BioMarin wants to pay via CC - sent email to Andrea
  - Food: - Need volunteers to bake/cook some of the items
  - Tools folder:
    - Recipes needed from group (toddler/kid friendly, baby foods, and family friendly meals?)
      - Andrea will help.
    - Any other tools we can provide? I will share my personal tools I created for diet journals, baby food tracking sheets, grocery store lists, any other ideas/support please send to Ami by 5/27
  - Decide who is doing what for Parent Café
    - What clinicians will be present to do a Q & A (2-3 people) Dr. Burton and Lurie Dietician Katherine Arduini are willing to volunteer for the new parent café in June
    - Who will be present to assist in set up (2 people) – Ami & Danae’
    - Who will help provide food (2-3 people) – Danae’ (Nutricia -
    - Who will help with donations , merchandise & board questions (1-2 people) - Ami & Danae’

### **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?

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.
- b. Cooking Demo. – Brenda from Cook for Love!!!
- c. Breakout sessions – 6 rooms available.  
We can do either a breakout or a panel. **We need to follow up on this....**

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.**

Either/Or

**How exercise/sports affects PHE levels...**

**-Maybe have Maryam from Vitaflo talk about Formula and sports...**

Breakout Session Idea:

**-How to optimize How Much PHE**

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

**V. PKU NATIONAL CONFERENCE**

When: July 28-31.

Where: Westin Downtown Indianapolis is located at 50 South Capitol Ave., Indianapolis, IN 46204

Who: Kim, Danae?, Matt, Pam, Ben, Dean and Clinicians will be in attendance.

