



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

PKU Organization of Illinois- Board Meeting

DATE: April 20, 2016

TIME: 7:00 p.m.

LOCATION: Arlington Heights Public Library

Call in Info:

Meeting Agenda

4/20/16

I. Roll Call

In person
Danae' Bartke
Matt Bartke
Grant Smith
Andrea Hall
Ben Wagner

On the phone:
Dean Seppelfrick
Mary Lonski
Hazel Vespa
Kim Kowalczyk
Lauren Kime
Soo Shim
Ami Vanderhoof
Joe Bonucci

Not in Attendance

Katie Pasiewicz
Eric Sartain

II. Officer Reports

A. **President's Report** – Danae' –

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

C. **Treasurer's Report**- Andrea –

-Let public know that many companies match their donations. This is a great way to gain additional donations.

Tax exemption certificate was received. A copy will be on the Google Docs account.

D. **Secretary's Report**- Matt – **Vote on minutes from last month.**
Matt put it on the table, Ben seconded it- All approved.

E. NPKUA Update – Kim –

New studies for the grant proposals will happen in June.

Andrea registered Kim for this event today.

Early bird discount ends 4/30/16

Katie Arduini, Soo Shim, Danae Bartke, and Dean Seppelfrick will be attending.

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-

Cambrooke -

BioMarin – Dekalb – April 9th, - follow up- 10-15 people showed up.

July 9th – Morton, Illinois – From the Field Cooking School.

Nutricia -

Camp – Pam & Ben – Camp site, activities – will be what we include for the cost.

See attachment from Pam about camp agenda.

**FYI - we need a FINAL head count one week prior to the event (Sept. 23- 25). That means NO ONE can register late.

Need to reach out to vendors for financial support, food donations, etc.

Nutricia is willing to donate food for camp – contact Mike Goldsher

Families will need to fill out waiver forms camp – Matt will put on website. Pam will email Matt the forms.

----> Camp contract is already faxed over as well as the proof of insurance. If people choose to stay in a hotel instead of staying at camp - there is a \$6 day user fee. I think it would be best if we kept just the pool/open gym at the same time for those who don't want to swim... and then have the option of the teams course with yard games. They Hayride is an additional cost, but it fun for all ages and most people have gone on the ride.

I am proposing that we tack on an additional 7 bucks per person to cover the team building course whether people choose to do this or not. It can be modified to a variety of ages. For individuals who do not choose to participate in the teams course - we will be having yard games and relays. The 7 bucks collected from people that are additional can be used to camp supplies.

B. Fundraising Committee -

Mongolian BBQ –

Mongolian BBQ Fundraiser

- Overview of program
 - Thursday, June 16, 2016 5:00-9:00pm – Naperville, Illinois
 - We are paid \$2 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 (I'm going to go to Mongolian to pick up current cards and revise to be low-pro) I'll have printed recipes available for PKU guests to enjoy a hot meal at the restaurant!
- 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"
- Do we have a tablecloth? – Yes, it's in storage.
- Scales (I might be able to get some from Nutricia?) **If Nutricia isn't able to, maybe we can provide them.**
- Flyer to distribute at events, social, email and email to our friends and family

Schaumburg High School Band Fundraiser –

Andrea received the cash donations. Need to contact the HS about the rest of the donation money.

Family Fun Day – Saturday, May 14, 2016 – extending registration till April 30th.

Dean and Danae' will be providing the food ☺

- Decide who is doing what at the Family Fund Day.
 - Who will be checking in people (2-3 people) (Need to check it against registration) Make sure number corresponds with registered amount – stamp hands for only those who are paid - this will be for their admission and lunch!
 - Andrea, Hazel,
 - Who will be selling raffle tickets (2 people) – Grant &
 - Who will be selling merchandise and accepting donations (1 person) – Ben?
 - Who will help monitor lunch (2 people) (should be checking stamps)
 - -Matt

Need to follow up with Cambrooke about event.

Wine event – Checkup- who has what – should have 3 donations per person.
-Contemplating raising the price.

Beer Garden – Dean Update – Is continuing to explore the idea- nothing is set though.

Bay Galvez Golf Outing – Andrea: Sunday Oct 2nd: This year we need someone there and speak. Grant will be in attendance.

-We need details! RSVP details.

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

C. Education Committee:

Scholarship-

Rubric – See attachment -

- 1; How PKU affects you and others
2. success with PKU
3. Challenges with PKU
4. How over coming 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 – Dekalb – April 9th, - follow up., July 9th – Morton, Illinois

Nutricia

Parent Café-

Parent Cafe:

- Flyer: Can we release now to get in front of families who are traveling?
- Vendor Support: BioMarin, Vitaflo, Nutricia, POA (so far: \$400 in vendor sponsorships)
- Vendor Tables: BioMarin, Nutricia, POA
 - 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**
- Checks: receiving vendor checks - can mail them to Andrea - BioMarin wants to pay via CC - sent email to Andrea
- Food: I had a brief conversation with Cambrooke (who sponsored last year) and she never returned two of my emails - we'd do one last attempt at following up - but we need a plan b just in case (I know 2 years ago, the food was brought by the board attendees - I'm happy to make some treats, but not sure how much I can do! can anyone else volunteer?) – **Danae' will follow up will Cambrooke.**
- 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 5/20
- 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' & Andrea**
 - Who will help provide food (2-3 people) – Danae' (Nutricia -
 - Who will help with donations and board questions (1-2 people) - **Ami & Danae' & Andrea**

D. Communications Committee

PKU Press- **Families should have received it by now via mail**

Articles 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**

a. Topic -

-Novel therapeutic approaches for inborn errors of metabolism including phenylketonuria, homocystinuria and others. – **This is the topic the board has voted on.**

-Patient registries – valuable resource for research, education and clinical management.

b. Speaker – Dr. Olaf Bodamer

Olaf Bodamer MD PhD FACMG FAAP

Associate Chief Division of Genetics and Genomics

