



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

PKU Organization of Illinois- Board Meeting
DATE: March 23, 2016
TIME: 7:00 p.m.
LOCATION: Phone Conference

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

Meeting Agenda

3/23/16

I. Roll Call

Danae' Bartke
Matt Bartke
Dean Seppelfrick
Kim Kowalczyk
Andrea Hall
Pam Kowalczyk
Ben Wagner

Lauren Kime
Mary Lonski
Hazel Vespa
Soo Shim

Not in Attendance

Grant Smith
Ami Vanderhoof
Katie Pasiewicz
Joe Bonucci
Eric Sartain

II. Officer Reports

A. President's Report – Danae' –

- Revisiting by laws – attendance rules
You must attend 3 consecutive meetings. After missing 4 or more consecutive meetings you are in violation of the bylaws.
Also, our presence is noted at events. Please make a strong effort to attend events put on by the board and the Vendors!

B. Vice-President's Report- Grant

C. Treasurer's Report- Andrea – Top 10 donors from 2015 – We need to reach out to them -Let public know that many companies match their donations. This is a great way to gain additional donations.

-Donations – we are at \$7,100

-P&L- \$9,750

Here are our big donors from 2015:

- Carmencita (Bay) Galvez - \$1500
- Heitman LLC - \$5000 (not sure if this company is doing a match or if the owner is related to the PKU community somehow. Check signed by Roger E Smith. 312-855-6523)
- Ketone Automotive (Greg Heindreich) - \$250
- Rosemary Steffes - \$1000
- Prominence Advisors (behalf of Andrea Hall) - \$500
- Robert & Christel Graham - \$200
- Network For Good - \$250 (networkforgoodcheck.org)
- Morgan Stanley (company match, I believe) \$114.58
- St. Bridget School - \$120 (3rd grade class did a fundraiser in honor of Lily & Thomas Nestler)
- Hazel Vespa (she's listed on our other list)
- Galvez Golf Outing - Several people at this event donated \$100+

D. Secretary's Report- Matt – Vote on minutes from last month.

Andrea put it on the table – Dean seconded the motion

E. NPKUA Update – Kim – Advocacy Committee – Teenager, Adult and Mentoring Program.

-Educational literature for the public and families affected

-PKU Patient Registry

Kim joined Research Advisory Board –

a. Pegvalcye – PH substitute – tested on non-compliant patients –

b. Probiotic Therapy – non a huge pool was tested from

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 @ Lil's – Was originally set for March 29 & 30 – Postponed

BioMarin – April 9th – NIU – another for June sometime in central illinois

Nutricia

Camp –

Need to get an agenda for the camp schedule

Team core

Tree climbing

Archery

Hay Ride

Pool

Open Gym

Nature Hike

Fishing Derby

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.

Grant – Can we have a drop down list of various options they can do at camp?

Notes from Pam regarding camp:

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

I am faxing in the contract tomorrow and I will call and ask about price of lodging if people choose to stay in a hotel rather than at camp.

I will also ask about how we figure in cost of additional activities.

Team building course - \$7 per person (3-4hr) archery - \$2.00 per person tree climbing - \$ 7.00 per person (3-4 hr)

We need proof of Insurance
and \$250.00 deposit

East Bay Camp & Retreat

[REDACTED]

[REDACTED]

I will work on a rough draft agenda

Food

Personally - I would like the dinner to revolve around campfire food for dinner - But I am open to other suggestions Campfire food - "walking tacos" "orange cakes" smores etc. We can also do a veggie stew in the crock pots if that sounds better!

all families attending should bring side dish/snack and breakfast item to share with campers (enough for 15 campers at least)

B. Fundraising Committee -

Mongolain BBQ – Pam, Dean and Danae' think it's a good idea.

-Maybe in the summer when the weather is nicer.

Reach out to local families in the area about the event once booked.

Schaumburg High School Band Fundraiser – \$127 in cash donations.

T-Shirt and Ticket sale proceeds go to the board.

Family Fun Day – Blackberry Farm, May 14, 2016

Who is doing what? – Email Grant or Danae'

We need 3 people at registration, 1 at donations, 1 selling raffle tickets and another running the merchandise table

Wine event – Everyone should have at least 1 donation by now – who has what.

Beer Garden – Dean Update – Is it worthwhile? The cost v. profit is getting less.

Looking at alternative locations for event

Bay Galvez Golf Outing – Andrea: Sunday Oct 2nd: 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-

Pam update on Rubric – will be looking – also needs to check the Google Drive account
Scholarship in PKU Press and Website – forms will be emailed to clinics

Cooking classes-

Cambrooke @ Lil's – Was originally set for March 29 & 30 – Postponed
BioMarin – April 9th – NIU – another for June sometime in central illinois
Nutricia

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.

Notes From Ami regarding Parent Cafe:

The location handles the registrations for us, since there is no payment, we don't need a formal check in.

- I'll be there a little early to let the vendors set up, and set up the food table - any help in set up would be great, but I don't expect to have much to do.
- I'll be collecting the vendor goodie bag donations in advance of the event, so I will have those put together prior to 6/11.
- Dr. Burton will present, and we will have a dietician from Laurie's there as well.
- What I would like to collect is recipes, and if anyone attending could bring low-pro treats.
- I think we should also have food and beverages for families (coffee, etc.)

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

- Vendors: Nutricia will be present with table, and providing GREAT kits for the families. Bio Marin will be present, and Vitaflo is confirming how they will participate - they have another event so cannot attend. I asked Cambrooke to supply the food, but have not heard back yet (yesterday). I have a follow up email going out tomorrow to all vendors as a reminder/recap

Notes from Soo Shim regarding Parent Cafe:

Dr. Burton and Lurie Dietician Katherine Arduini are willing to volunteer for the new parent café

in June

D. Communications Committee

Press to go out- as of today!

Articles for PKU Press

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

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

a. Topic - .

b. Speaker – Dr. Olaf Bodamer

Olaf Bodamer MD PhD FACMG FAAP

Associate Chief Division of Genetics and Genomics

Park Gerald Chair in Genetics and Genomics

Director of the Boston Children's Lysosomal Disease (BoLD) Program

Boston Children's Hospital/Harvard Medical School

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.

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 12th

e. Find a new cooking demo person. Need to follow up on this - Brenda from Cook for Love, Fabio from Letizias. Malathy from Taste Connections.

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. Clinicians will be attending too.

