



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

PKU Organization of Illinois- Board Meeting
DATE: 10/28/15
TIME: 7:00 p.m.
LOCATION: Arlington Heights Library

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

Meeting Agenda

9/9/15

I. Roll Call

In Attendance: Pam, Ben, Grant, Danae', Matt, Andrea

On the phone: Hazel, Mary, Jacob, Lauren, Soo

II. Officer Reports

- A. **President's Report-** Annual Meeting is coming up. Framework is done, just needs to finalize details. Jeanette Amaya, has MSUD and would like to speak during the annual meeting about her experience with MSUD for about 10 minutes.
- B. **Vice-President's Report-** Cambrooke's food is all ordered. Food will be mailed directly to Eric. We were unable to get as much as he requested, but Eric is aware. Hotel is going to match the "regular food" to the PKU Meal. Hotel room is booked for Kendra.
- C. **Treasurer's Report-** Andrea has not been able to finalize loss - profit report. Sixty -seven people attended the Wine Tasting. That was a record high.

Dr. Galvez- Golf Outing Director. We

In January we will look at the bi-laws and see if we can find a way to extend the executive roles or expand our board? Are the clinics aware of anyone who may be interested?

D. **Secretary's Report -** Unfilled

E. **NPKUA Update** – Danae' has email to share about NPKUA Voting Status -

III. Committees 2015

A. Hospitality Committee

Cooking classes- Follow Up – Morton, Illinois cooking class with CamBrooke was a success. Ten people came. CamBrooke thought it was a success and would like to host another. One of our guests was from St. Louis.

Camp – On hold
Parent Café – Completed

B. Fundraising Committee

Family Fun Day- Completed.

Wine event – Follow Up:

Andrea has not been able to finalize loss - profit report. Sixty -seven people attended the

Wine

Tasting. That was a record high.

Venue was a little snug and parking was a hassle, but the food and atmosphere made up for it!

C. Education Committee:

Scholarship Winners:

- Marissa Pratscher- Unsure if she is going to be attending.
- Michelle Brandon – Michelle will be present to accept Scholarship
- Taylor Hardy – Unsure if she is going to be in attendance, Andrea has followed up.
- Garrett Austin – Garrett will be present to accept Scholarship
- Is there a 5th person for sure? Eric Sartain and Alex Seidler applications were incomplete.

D. Communications Committee

- Discuss creating T-shirt design

- Board for Next year, who is rolling off, who is staying and who is doing what?

-President – Danae’ Bartke

-Vice President

-Treasurer

-Secretary

-NPKUA Rep. –Mike Schauer

-Camp Directors- Ben & Pam

-Golf Committee-

- Other Volunteers

- Those possibly joining or are joining.

- Ami Vanderhoof –Parent Café & Cooking Classes,

- Joseph Bonucci,

- Dean Seppelfrick- Wine Tasting,

- Mike Schauer – NPKUA Rep (Melissa Sujak’s father)

- Jump Zone Event -

-Rolling off the board

-Haley Walsh

- Margaret’s Email about state budget

- If we address this, it may cause more harm than good.

- CamBrooke needs to contact the state with their concerns about the budget. Any further issues Grant would be glad to address.

E. Financial Planning committee

Headed by Andrea –

IV. ANNUAL MEETING

- a. Topic - PKU Milestones
- b. Speaker – Annual meeting speaker is secured – Neuropsychologist, Dr. Kendra Bjoraker.
- c. Breakout sessions – Age group and Allied Health Disorder – Finalize Details of Breakout sessions > Time > Who is doing what > topics to be addressed >

Breakout sessions will be at 11:45 – 12:30

Ben will be finalizing breakout session room arrangements. We will not have them moving rooms once they are set.

Who is leading what:

Early Childhood- Katie Pasiewicz & Amanda Aspen – Lurie Dietician

Elementary - Gallagher Family maybe? & Lauren from UIC

Middle School- Katie Ardini from Lurie's

High School- Andrea Paras

Adult Group – Sarah Marshall & Heather Ricca(?) (Is there enough people and space to have Heather do a Maternal PKU Breakout Session?) Heather Bassel at Luries

Allied Health Disorder – Danae' Bartke - Rich Bienen (spelling?) – Soo Shim

Children's Group- Brittany, Child Life Specialist

-Ruthie, Miss Illinois is going to make an appearance.

Possible Topics for:

Psycho – Social Development Milestones

- **Birth and Early Childhood** – How to handle the switch over from formula to foods

-Tips and Tricks for Blood Test

-Navigating Birthday Parties

-Handling Daycare and the diet

-**Elementary**- PKU PHE Chart (a way for kids to help keep track of their phe)

-504 Plans for Formula and any other behavior issues

-Navigating Birthday Parties

-Adapting school lunch programs with the diet

-**Middle School** – Involving kids in meal planning and cooking.

-Having kids keep track of their PHE with parental assistance via phone APP or paper food log.

- **High School** – How to help prepare them for the transition to being adult and in college.

-How to speak to colleges about diet requirements (if living in the dorms).

-How to handle study abroad programs.

- **Adult Group** – managing a family and PKU

-managing work and the PKU Diet

-maybe she could discuss how she plans food for the week and any recipes that are
the working adult with PKU.

-the importance of finding time to exercise and the correlation it has with PHE levels.

As far as Heather Ricca, maybe it would be a good idea for her to also be there. If I recall, correct me if I'm wrong, but I don't think Sarah has children. I think Heather would be a great segue in to how to handle becoming and being pregnant with PKU. Having two successful pregnancies this would be a great highlight for women with PKU wanting to have children.

- **Allied Health Disorder**

-**Children's Group** (only if necessary)

d. Location- Holiday Inn Skokie

-Need volunteers to bring breakfast items

-Holiday Inn is providing non – PKU Food

-Danae' is providing PKU Breakfast

- Do we have any videos? Would any board members be willing to make one?

-No more videos ☹

V. NPKUA National Conference

Attending:

Call In:

Not Attending:

great for

