

PKU Organization of Illinois

P.O Box 102 Palatine, Illinois 60078-0102

PKU Organization of Illinois- Board Meeting

DATE: July 22, 2015 TIME: 7:00 p.m.

LOCATION: Arlington Heights Library

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

Conference Call Meeting Minutes

7/22/15

I. Roll Call

II. Officer Reports

A. President's Report-Pam. Fundraising – looking into contacting bigger companies on a corporate level - for example insurance companies or AMC. This should be done earlier in the year before they run out of money.

Grant suggested keeping our budget and donations visible to the public so the public is aware where our funds are going towards. We need to set fund raising goals.

We will present the revenue raised and where it went at the annual meeting this year.

- 1 Grant will email Andrea tomorrow to get the info
- 2 Grant will make the slides for the annual meeting
- **B. Vice-President's Report-** Ben. Updates.
- C. Treasurer's Report- Andrea. Budget updates.
- **D.** Secretary's Report- The open PKU board positions for 2016 were presented in the PKU press.

Jacob will roll off

Andrea will roll off

Melissa will roll off in October 2015

Pam and Ben will roll off as President and VP but will stay active

We have 2 people possibly interested in participating on the board in 2016.

E. NPKUA Update –Danae. Home PHE monitor has issues with accuracy. NPKUA is looking into other fundraising opportunities and reaching out to other communities to make a larger impact when presenting to congress.

III. Committees 2015

A. Hospitality Committee

Cooking classes- Naperville Cooking Class sponsored by Nutricia on Saturday 7/25. Asian cooking theme. Currently at 25 people registered. Anticipate about 20 people to show.

Lurie's staff will be hosting a Grocery Tour at Lils Dietary Specialty Shop 8/20 from 6:30-8p. Posted on Website and Facebook and Constant Contact.

Camp – On hold. We are having another cooking class in Morton Illinois 9/19. Cambrooke will be hosting it. Grant to send out constant contact. Cambrooke needs to have good attendance to continue to host future cooking classes. They want a minimum of 20 people.

Parent Café – Completed. Positive feedback. People enjoyed having PKU food to sample. This is something we will continue to provide.

B. Fundraising Committee

Family Fun Day- Completed.

Wine event -

Discussed other fundraising opportunities – Golf outing or Gala for the metabolic community. We need someone with knowledge of how to put these events together. Grant stated we need a corporate sponsor to pay for the food and the course to be able to generate profit for an event like this.

Pam suggested a bowling alley event to make it more of a family friendly activity.

Danae will reach out to Christine to see what events are being held throughout the nation to raise funds.

Hazel will talk with the owner of Chicago Detours and ask if she is interested in sponsoring a PKU event.

At the annual meeting we will reach out to the community to generate other fundraising opportunities.

C. Education Committee:

Scholarship – We have not received any scholarship applicants. Grant will post on facebook. Board voted that those eligible for scholarship should be an Illinois resident or treated at an Illinois clinic.

D. Communications Committee

PKU press-done.

Discussed creating T-shirt design instead of changing the logo. We can announce this at the annual meeting and have it closed after Christmas and make a vote at a board meeting.

Danae stated we need to have it documented how much it will cost to make a T-shirt so we can make a profit.

Grant will send out constant contact for wine tasting and cambrooke cooking class. He will also send save the date for annual meeting.

E. Financial Planning committee

Headed by Andrea – money to be dispersed – where, when, etc. Biomarin only gave \$1000 for grant rather than the usual \$5000.

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 (we need to reach out to the clinics and pku representative to lead groups). Pam will contact the MD at Rush to invite them to the annual meeting and to be more involved in the community.
- d. Location- Holiday Inn Skokie

Cooking demonstration- Discussed alternative options for this segment. Danae suggested using Christine Ranieri Metabolic RD, The Chef from Latizia, Tim a Certified Chef (he

owns a starbucks), or the PKU Chef (Samantha Meyers from California). We need to f/u with Andrea to see if we have money allocated for this. Grant suggested having a "lunch like me" demonstration.

Call in: Pam

Ben

Grant

Matt

Danae

Melissa

Hazel

Mary

Jacob

Not Attending:

Kate

Andrea