

PKU Organization of Illinois- Board Meeting DATE: 9/9/15, 2015 TIME: 7:00 p.m. LOCATION: Arlington Heights Library

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

Meeting Agenda

I. Roll Call

9/9/15

- II. Officer Reports
 - A. President's Report-Pam. Updates. ben is staying in contact with eric about food. Eric will be cooking a PKU meal that is comparable to that of what will be served by the Holiday Inn it would be too difficult to cook that much food in the small amount of time.
 Pam will be contacting the Caro family about the mexico trip and finalizing.
 - B. Vice-President's Report- Ben. Updates.
 - C. Treasurer's Report- Andrea. Budget updates. See wine event
 - D. Secretary's Report- Melissa. Updates. LAST MEETING WAS TODAY!!! GOOD LUCK MELISSA!!!!
 - E. NPKUA Update Danae. Updates. NO UPDATES MEETING ON SUNDAY

III. Committees 2015

A. Hospitality Committee

Cooking classes- Morton Grove Cooking class 9/19 sponsored by Cambrooke. – next Friday – 15 people registered as of right now. Danae is finalizing details with Margaret tomorrow. – menu, recipes, etc.

Camp – On hold. – **PAM WILL BE CAMP DIRECTOR/LEAD 2016 and JEN WURSTER EMAILED PAM AND HAS STATED THAT SHE WOULD LIKE TO BE INVOLVED WITH CAMP AS WELL**

Parent Café – Completed.

B. Fundraising Committee

Family Fun Day- Completed.

Wine event – Andrea update. List of Donations. Big ticket item.

WE ARE STILL GOOD WITH THE RESTAURANT. MENU WAS EMAILED TODAY – PRETTY MUCH THE SAME. STILL LOOKING FOR MORE DONATION. WE NEED A MORE DETAILED INFORMATION OF WHAT IS ACTUALLY BEING DONATED. APPLE WATCH WILL BE THE BIG TICKET ITEM FOR WINE EVENT. IF YOU HAVE NOT REGISTERED FOR WINE EVENT DO THAT ASAP! (BEFORE GRANT EMAILS US AGAIN! ;)

From Grant's EMAIL : "as of this moment, there are 20 people registered for the wine event, 8 of which are board members (danae, grant, hazel, jacob). Which also means THE REST OF YOU STILL NEED TO REGISTER!!!"

C. Education Committee:

Scholarship – Applicants – Michelle Brandon, others? WE HAVE MORE APPLICANTS!

- Eric Sartain
- Taylor Hardy
- Marissa Pratscher
- Garrett
- Alex Siedler

D. Communications Committee

PKU press- Press done and mailed out. Discuss updates on HIPAA compliance. –WE ARE NOT A HOSPITAL SO IT SHOULDN'T BE TOO BAD – HOWEVER, NEXT YEAR, WE WILL ADD A DISCLAIMER ON THE BOTTOM OF ALL OF OUR REGISTRATION PAGES STATING THAT PICTURES WILL BE TAKEN AND POSSIBLY USED FOR PKU PUBLICATIONS INCLUDING NEWSLETTER AND PKU ORG OF IL FACEBOOK AND WEBSITE

Discuss creating T-shirt design.

DANAE WILL PUT A TEMPLATE OF A TSHIRT (FRONT AND BACK) ALONG WITH THE RULES FOR THE DESIGN IN THE FOLDERS AT THE 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

Sarah Marshall will lead a group – Sarah will be leading the adult group.

**many of the Lurie staff would be willing to lead our PKU annual conference breakout sessions this year! ANYOTHER VOLUNTEERS TO LEAD? THERE HAVE NO BEEN ANY VIDEOS TURNED IN AS OF

RIGHT NOW – CAN WE DO SOME MEDIA BLASTS?

Children's group – Child life specialist Brittany. Each child will draw a picture, write, or make a collage on a stone representing the most memorable PKU milestone for them.

d. Location- Holiday Inn Skokie

Cooking demonstration- Eric Sartain. PKU and non PKU friendly meal demonstration. – CHANGED TO ONLY MAKING A PKU MEAL THAT IS COMPARABLE TO WHAT HOLIDAY INN WILL BE SERVING DUE TO TIME CONSRAINTS

Need volunteers to bring breakfast items

V. **PKU National Conference**

Make Wine Tasting Poppers Tonight!!

Attending:

Call In:

Not Attending: