



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

PKU Organization of Illinois- Board Meeting

DATE: 2/22/17

TIME: 7pm

LOCATION: Payville USA – 800 Enterprise Drive, Suite 201, Oakbrook, Illinois

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

Meeting Agenda

I. Roll Call

- Danae
- Grant
- Kim
- Andrea
- Sean
- Elena
- Matt
- Mary- On the phone
- Soo Shim – On the phone
- Shannon Obrien – On the phone
- Absent: Ami, Katie.

II. Officer Reports

**A. President's Report –
None**

**B. Vice-President's Report-
None**

C. Treasurer's Report-
We completed the budget for 2017.
Ami needs more Bios

D. Secretary's Report-

- Feb 28th: World-wide Rare Disease Day – post to social media about this.
- April 1-30th: Virtual Denim Dash 5k
- Will Update calendar of events after this meeting

E. NPKUA Update -

- Annual Affiliate Activity report due 3/16/17 – already sent.

- PKU patient registry – Grant has posted on our sites. Will post the Back to Care Coalition soon.
- SEND NPKUA our schedule of events to help promote
- Elena to meet with FDA regarding Pegvalia advocate

III. Committees 2017

A. Jump Zone

- Niles – 3/11/17 - Confirmed
- 100% of the door money can go straight to the organization.
- \$11/person - no up-charge necessary
- Sent out an email for people to RSVP but has not had any responses.

B. Mod Pizza

- Naperville – 4/4/17 - Confirmed
- Glenview - ???April or May
- MOD will not let us use Mevalia crusts, so we will use their gluten free crusts.
- Will be getting a flyer from them in early March. Must use their flyer, anyone who uses that flyer during the entire operational hours, we will get their proceeds.
- Once we get the flyers, Matt will put it on the website and will hope to put it in the PKU press.

C. Family Fund Day

- Blackberry Farms, Aurora – 5/20/17 – Confirmed
- We are on the lawn
- Registration (Before April 29th): \$32/adult, \$24/child. (After April 29th): \$40/adult, \$30/child.
- Registration Deadline: 5/13/17
- Danae to follow up with Holly (the director) to clarify about food requirements regarding catering on their preferred vendor list, vs bringing our own outside catering.
- Chairman to get in touch with committee members for planning.

D. Parent Café

- Grounds for Hope, Lisle – 6/10/17 – Confirmed

E. Mongolian Grill

- Naperville - 6/15/17 - Confirmed
- 5:00-9:00pm
- 2 guest grillers
- This time we get 80% of whatever tips end up in both jars - not just the one
- We also get \$3 per person that comes in to eat

F. Lagunitas

- Booked for 2017. They require a liquor license. We will hold off until next year and find a new venue.

G. Camp

- Great Oaks Camp, Lacon, IL 8/25-8/27
- \$45/person, including all activities, lodging, and meals.
- Grant from Biomarin for people who would like to go but are unable to afford it.

H. Top Golf

- Naperville – 9/17/2017 - Confirmed
- 3:30 to 6:30 PM
- Total cost for 21 guests: \$873.71
- Pricing? \$100/person, \$175/couple, \$300/foursome
- Includes food and golfing, not drinks
- Over half the proceeds are going to PKU
- Can manipulate the food menu until the day before. Grant will talk to Top Golf to accommodate PKU diets

I. Wine Tasting & Silent Auction

- Enoteca Roma – 10/7/2017 - Confirmed
- 5-9pm. We will get there at 5 to set up, guests to arrive for event start time of 5:30pm
- Will serve wine 5:30-8:30
- Will use Gesture again, Pull-a-Cork.
- Price \$65/person, \$100/couple
- ALL NEED TO DONATE ITEMS FOR THE AUCTION. Each person to obtain 1 item each month.

J. Annual Meeting

- Doubletree suites, Downers Grove, IL – 11/4/17 - Confirmed
- \$13,080 includes AV. This also includes tax, but we are non-profit and are not responsible for tax.
- Chef is willing to accommodate – Mexican themed menu.
- Andrea will help seek out guest chef. Fabio to do a demonstration? Prefer to find a local chef to save money on hotel stay of other chefs.
- Has a salon/spa – encourage guests to spend the night and enjoy the amenities.
- Price \$35/adult, \$20/children, Medical Staff free. Danae will ask venue about children's price.
- Keynote speakers: Dr. Harding/CRISPR. If he is not available, is there someone that can speak on his behalf about CRISPR and how it relates to metabolics.

K. Cookie Exchange

- Kowalczyk house vs Grounds for Hope (affiliated with a church, has a coffee shop inside)
- Another chairman willing to host at Grounds for Hope?

L. PKU Press

- Shannon O'Brien - Ask Phebee article
- Ami - Recipes - (2-3 recipes)
- Ami - Board member bios
- Ami - Event Flyers
- Kim - Special interest article
- Danae' - Follow up with scholarship winners
- Danae' - Will ask vendors and clinics for any events they'd like promoted.

- DEADLINE FOR ALL ARTICLES: February 28.

- Cambrooke's Article – Danae will forward that to everyone. Everyone read it and respond to Danae about your opinions about whether to include it in the press or if it appears to be a conflict of interest.

M. Vendor Events or News

- Proprionic Acidemia Foundation - sponsor table at their meeting in Deerfield, June (8-10th)? It would be a minimum of a \$500 sponsorship.
- Can we sponsor a break (buy the break food and pass out our flyer), or the AV equipment, rather than sending a group and setting up a table for \$500.
- Grant can give a short speech during coffee break if needed.

IV. PKU NATIONAL Lobby Day

- May 21-23
- Lobbying in Congress
- Kim will be going

V. Hospital Update via Soo Shim:

- Teen day workshop on education and diet ages 12-18, will let you know when we have a date
- Boot camp in October at Luries. Parking and transportation assistance, free dinner. Other patients from other clinics are welcome.

- Hazel will helping with wine event
- Soo shim will follow up with clinic about Parent café
- Either Soo or Hazel will be at Blackberry Farms.

- Shannon O-Brien – no current updates from Rush.

VI. MISCELLANEOUS

- PKU perspectives – lead by Elena Caro
- PKU policy and its implications – email all of us individually to interview us about our opinions.
- Will eventually write up a report about all of the information.

Attending:

Call In:

Not Attending: