



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

PKU Organization of Illinois- Board Meeting

DATE: 3/8/17

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

#### Attended:

- Danae Bartke
- Matt Bartke
- Grant Smith
- Elena Caro
- Kim Kowalczyk
- Ami Vanderhoof
- Andrea Bianculli-Hall

#### Call In:

- Mary Lonski

#### Not Attended:

- Sean Haney
- Katie Pasciewics
- Soo Shim
- Shannon Obrien
- Hazel Vespa

### II. Officer Reports

#### A. President's Report –

- Vendor sponsorship forms sent to all of the vendors. Then sent them to all of the chairmen to see what sponsors we have for each event.
- Cambrooke changed donation process. Gave money allotment of how much money we could spend \$1250 over the course of the year.
- Food committee member for each event to get in contact with the vendors for food donations.

#### B. Vice-President's Report-

- Looking into crowdsourcing fundraising website

**C. Treasurer's Report-**

- Insurance is due this month
- Checks to deposit

**D. Secretary's Report-**

- April 1-30<sup>th</sup>: Virtual Denim Dash 5k
- Calendar of events has been updated, alerts for meetings have been added

**E. NPKUA Update -**

- Sent NPKUA our schedule of events to help promote
- Back to care coalition has launched
- Medical Nutrition Equity Act – Bipartisan support now with the addition of Senator Grassley
- Lifting the Limits in Buffalo has raised 19K
- Patient registry – 466 patients
- Biomarin delayed filing of Pegvaliase

**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, 11 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.
- Received flyers for Glenview, not for Naperville, Danae will investigate.

**C. Family Fund Day**

- Blackberry Farms, Aurora – 5/20/17 – Confirmed
- We are on the lawn
- Registration (Before April 29<sup>th</sup>): \$32/adult, \$24/child. (After April 29<sup>th</sup>): \$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.
- Matt will get registration links for all events on the PKU webpage.

**D. Parent Café**

- Grounds for Hope, Lisle – 6/10/17 – Confirmed
- 9:30-11:30am
- FREE – no registration table/check in time
- Will put together goodie bags again, look into vendor support.
- Will need vendor tables.
- Cambrooke will be willing to do a waffle bar.

- Possibly a Q&A session/panel.
- Outreach to the clinics: Have them hand out flyers to their new families
- Katie from Lurie's has a shopping list to provide.

**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
- Bring a set of measuring cups, possibly a scale.

**F. 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.
- Need to give owner, Paul Tanner, final head count and schedule of our events at least 10 days prior to our event.
- Danae will create a new tab on the PKU page just for camp, including details like a camp agenda, menus, and a map.

**G. 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

**H. 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
- Price \$65/person, \$100/couple
- Will use Gesture again, Pull-a-Cork.
- Andrea will look into purchasing Gesture for the entire year, will follow up with the cost for the year. For just the wine tasting it will be \$1500.
- ALL NEED TO DONATE ITEMS FOR THE AUCTION. Each person to obtain 1 item each month. Focus on themed baskets. Shoot for 20 items.
- Ami will send out tips and strategies for collecting corporate donations

## **I. 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, \$25/children, Medical Staff free. Children's fee moved up \$5 from last year to accommodate for venue's policy regarding no children's discount.
- Children must be 6-12 years old to join the children's program
- Keynote speakers: Dr. Harding/CRISPR: His graduate student, DAELYN RICHARDS, is actually doing the work on the NPKUA funded CRISPR work, and will show the efficacy of this technology to treat disorders like PKU. Dr. Harding is unavailable, Richards confirms that she will speak on his behalf!
- Break out sessions: Dieticians to talk about the How Much Phe app, Heather Ricca to lead a session for maternal PKU, sports and PKU,
- Panel as a break out session vs panel as a separate activity, and lengthen the day. Maybe keep them separate and have the break out sessions at the end of the day.

## **J. 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?

## **K. PKU Press**

- All articles are in for the Spring Edition
- Ami - Recipes - (2-3 recipes) – Use Cook for Love recipes.
- Will add in NPKUA patient registry flyer.
  
- FALL PRESS DEADLINE: June 30th

## **L. Vendor Events or News**

- Proprietary 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.

## **VI. MISCELLANEOUS**

- WOOHOO Elena FDA rep!!!