



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

PKU Organization of Illinois- Board Meeting

DATE: 4/12/17

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

Matt

Grant

Kim

Call In:

Elena

Shannon

Soo

Not Attended:

Andrea

Ami

Katie

Sean

Mary

Hazel

II. Officer Reports

A. President's Report –

None

B. Vice-President's Report-

Looking into crowdsourcing fundraising website

Will do it for November Annual Meeting, we are paying \$110/person and only charging \$30/person.

C. Treasurer's Report-

N/A

D. Secretary's Report-

- April 1-30th: Virtual Denim Dash 5k

E. NPKUA Update –

Christine Brown LOVED our PKU press! She was very complimentary of it.

III. Committees 2017

A. Jump Zone

- Complete!
- 15 people – owner chipped in another \$250 = \$415 total

B. Mod Pizza

- Complete!
- \$15.15 from Glenview. \$98.34 from Naperville

C. Family Fund Day

- Blackberry Farms, Aurora – 5/20/17 – Confirmed
- BIOMARIN GRANT HAS BEEN ACCEPTED
- 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.
- PKU tacos for the menu
- Chairman to get in touch with committee members for planning.
- Matt will get registration links for all events on the PKU webpage.
- We will have a patient registry table with computer to promote NPKUAs motion to increase their volume of registered patients, and they can register in real-time
- Kim will make a sign, buttons, stickers, etc

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.
- BioMarin grant is pending
- Around the world theme menu
- Kim will get in touch with committee members about activities
- Need to put in low protein food requests to vendors by July
- 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
- Danae' will send out a spreadsheet to keep track of 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 is interested in attending, she is looking up her availability.
- 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.
- Need a theme. Mission Possible?

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

- Spring Edition Complete!
- Has been printed and is in the mail
- FALL PRESS DEADLINE: June 30th

L. 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.
- The PA Foundation will gladly accept the \$500 sponsorship, and will be willing to have our information out on a table
- 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 – meetings BOOKED for Duckworth, Schakowsky, and Quigley. Still working on Dick Durbin.

V. Hospital Update via Soo Shim:

- Teen day workshop on education and diet ages 12-18
- July 13
- 11am-3pm at Luries
- Free Parking
- Open to All
- Sean Haney will be a speaker
- In the process of making a flyer
- Shannon to find out about another “HowMuchPhe” app that is free. May be international app, and foods may be measured out differently.
- Boot camp in October at Luries.
- Vera Shipley is a new member at Lurie’s who is creating more patient education materials.

VI. MISCELLANEOUS