



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

PKU Organization of Illinois- Board Meeting

DATE: 8/16/17

TIME: 7:30pm

LOCATION: CALL IN ONLY! (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 –  
Grant Smith –  
Ami Vanderhoof  
Matt Bartke  
Andrea Hall

#### Call In:

Soo Shim  
Mary Lonski  
Sean Haney

#### Not Attended:

Kim Kowalczyk  
Elena Caro  
Shannon O'Brien  
Hazel Vespa

### II. Officer Reports

#### A. President's Report –

Who is staying on the board and with what role. We need to figure out a roster by November. Matt, Danae, and Andrea are rolling off Andrea will still help organize the wine tasting and Matt and Danae will help train the new board members in charge of the website. Ami will not take on treasurer next term, but will still be on the board. Hazel will continue to volunteer with event planning.

Need to fill president, treasurer, and web site administrator. At large members?  
Shannon O'Brien is rolling off - Krista Engen from UIC will take her place.

Marissa Pratcher – Loyola student, interested in joining the board. Pre-Law.

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

**August** is the last to figure out crowdsourcing for annual meeting

Grant, Danae' and Andrea to schedule a call with flipcause

-Scheduled for 8/22/17

**C. Treasurer's Report-**

Skipped

**D. Secretary's Report-**

Skipped

**E. NPKUA Update –**

- Christine Brown and Amy Oliver met in Toronto with many other PKU leaders from around the world and have implemented an International PKU Organization. Name of group to be determined.
- We have another republican Cosponsor for the MNEA (Walter B. Jones – NC)
- PKU registry is at 671. We are looking for **“Registry Helpers.”** A Registry Helper is an individual who would be willing to work one to one with a PKU adult who is interested in entering their information but may require a little help. This could be done in person or over the phone. We have received inquiries from affected PKU individuals who would like to participate but have are having issues with the necessary steps that are required. If you know of someone who may be interested in supporting a PKU adult in this way, please have them contact me and I would be happy to discuss this further.

**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**

- Complete!
- Recap? 70 wrist bands out of 82 registrants.
- Next year – June. And then move Parent Café to May because it is indoors

**D. Parent Café**

- Complete!
- Recap? Exact number unknown (roughly 45), but at least 80-90% of registrants showed up.
- Huge success. Great to have Elena highlight her successes. Everyone loved the gift bags. Margaret from Cambrooke's read a story, Grant lead a Q&A that all had very positive feedback.

**E. Mongolian Grill**

- Complete!
- Raised \$200. Maybe not so far into summer – Food fundraiser – Let's try avoiding summer months.

**F. Camp**

- Great Oaks Camp, Lacon, IL 8/25-8/27
- \$45/person, including all activities, lodging, and meals.
- Low registration numbers: Currently at 19. Possible maximum of 20.
- Might have to be doing with timing. Conflicts with school schedules.

- Kim to confirm final registration with Paul.

**G. Top Golf**

- Naperville – 9/17/2017 – Confirmed –Currently 15 people registered.
- 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. Everyone has signed up for a basket. Need to be in to Ami by September 1<sup>st</sup>. Look at 5Below for filler items.
- If we have an over-flow of auction items, will just use them for the Annual Meeting.
- All items should be in the google docs that was shared – the value and please send the pictures to Ami, Andrea, and Danae'

## **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.
- Working on the save the date, Ami will get that to Danae by the June PKU press deadline.
- Chef is willing to accommodate – Mexican themed menu.
- Rachel Merz – Confirmed guest Chef
- 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.
- Topic discussion for MNEA and the NPKUA in Washington DC. Kim will speak about it (20-30 minutes)
- Breakout sessions (30 minutes) just before lunch:
  - \* Dietary best practices – eating habits, tracking, how much phe – etc.
    - Cambrooke low protein lunches & 504 plans – maybe direct to website
    - \*Need to find RD and patient rep
  
  - \* Athletics and Metabolic Diets –
    - \*Sarah Marshall 8/22/17
    - \*Maryam (Vitaflo) em 8/22/17
  
  - \*The Early Years – What to expect –
    - \*need to find RD and patient rep
- Can do a panel right at the end of the day
  - Grant – Moderator
  
  - Soo Shim – insurance assistance and Q&A
  
  - Meredith Stutzman – (not confirmed) emailed – 8.22.17
  - Christina Scorrt McDowell, son (dad not needed) – Middle School (not confirmed)
    - Emailed 8.22.17
  - Elena (not confirmed) emailed 8.22.17
  - Sean (confirmed!)
- Mission Possible theme
- Postcards will be mailed by 9/1/17

## **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!
- Fall Edition Complete!

**L. Vendor Events or News**

- The Propionic Acidemia Foundation complete- very well attended by researchers and doctors. Very serious tone stressing the importance of further Research.
- Nutricia - hosted cooking class, August 19<sup>th</sup>, at Naperville 95<sup>th</sup> street community center. 32 registered – Really great feedback by those attended. Pictures are online.

**IV. Hospital Update via Soo Shim:**

- Teen day workshop complete! 12 Teens – Sean and Elena attended, clinic reports they did a fantastic job.
- 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 – No specifics yet.

**V. MISCELLANEOUS**

- Mary’s PKU ribbon fundraiser: Still at 160