



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

PKU Organization of Illinois- Board Meeting

DATE: 10/18/17

TIME: 7:00pm

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
Elena Caro
Kim Kowalczyk
Grant Smith
Andrea Bianculli-Hall

Call In:

Mary Lonski
Melinda Halvorsen
Soo Shim
Shannon O'Brien
Alex Seidler

Not Attended:

Ami Vanderhoof
Katie Pasciewicz
Alex Siedler
Hazel Vespa

A. Officer Reports President's Report –

Scholarship winners:

Ashleigh Ginter
Sarah Lowery
Sarah Marshall
Haley Walsh
Heather Ricca

Need another board position to process scholarships (2 people should be in charge to read these over)

Create a rejection letter for scholarships: Grant to write it and send it out. Danae will email Grant a copy of the acceptance letter.

At annual meeting, discuss with the vendors, any questions that they have need to be asked to the Vendor rep. Alex or Laurie Bonucci to attend meeting to take these questions. If need any supplies, take this to the event coordinator (Jose) to address them.

Propose a new role for the team next year. Called Gopher and it will be the responsibility to go to the storage unit for all events. Can be a different person for each event. Located in Palatine. Will switch lock from padlock to combination lock.
Another person in charge of the mail. May just be the job of the Treasurer since they have to process the mail anyways.

Subdivide PKU press: editor, writers, and flyers.

B. Vice-President's Report-

Flipcause update – Had the call, they were deceptive and will not save as much money as we originally thought. Will not sign up but may be a possibility in the future.
Slack is up and running!
Salesforce for non-profit is still open.

C. Treasurer's Report-

D. Secretary's Report-
None

E. NPKUA Update –
Kim and Elena to meet with Representative Roskam tomorrow to discuss MNEA!

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

- Complete!
- Great turnout! 22 overnights, +1 for Saturday
- +\$181 left over
- Survey responses: 5
 - 2 want same weekend, 2 wants earlier
 - 4 want to cook a meal, 1 doesn't
 - All 5 want to bring a dish for a pot luck
 - All loved all activities (esp lake time)
 - Nobody disliked any activity
 - Activity for next year: cooking demo, eating contest, board games, parent/caregiver activity, that SWEET ropes course
 - Changes: a functional blob, more families, candy or fun snack food.

G. Top Golf

- Complete! Recap?
- \$1475 net profit including donation by Nutricia.

H. Wine Tasting & Silent Auction

- Complete! Recap?
- \$4995 net profit with a \$5 donation by Andrea to make is \$5k.
- Gesture helped out Tremendously, Ami got all of the wine cork donations, and the venue contacts.
- Andrea gave feedback to Gesture, only one picture would show up on the app. Has a call planned with Gesture too for constructive feedback as well.
- Andrea will get recipes from Fabio from wine tasting to put it on the website.

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.
- Price \$35/adult, \$25/children, Medical Staff free. Registration closes 4 days beforehand.
- Rachel Merz – Confirmed guest Chef.
- Grant will buy Tupperware for the guests
- Children must be 6-12 years old to join the children's program presentation (joining the rest of the meeting) at about 3pm. Lead by Brittany, Kim to volunteer. Children can help distribute raffle prizes.
- Andrea Aras genetic counselor to do the educational program. Researchers are volunteering.
- Margaret for cooking demo. Melinda and Andrea will bring toaster ovens.
- Mary to sell her ribbons at a table next to the T-shirt sale
- Keynote speakers: DAELYN RICHARDS. CRISPR - the efficacy of this technology to treat disorders like PKU.
- **Daelyn Richards has confirmed attendance!** She is coming Friday. Kim to email Daelyn for dinner with the board Friday night, and to email the board if any other member would like to join.
- Soo Shim - Dr. Burton will attend and may be able to talk on multiple topics. Hazel – Check in with Dr. Burton or U of I
- Melinda to help put together annual meeting folders: Article about CRISPR, NPKUA funded research
- **WE NEED AT LEAST 3 PEOPLE ON REGISTRATION 8:15 -8:55am. Andrea and Kim to do registration, Corey to run merchandise. Most volunteers will be with the Children's Program which starts at 8:50.**
- **Need to make signs with arrows to the Corporate Center for all guests. Danae to ask Jose/Hotel to make these directional signs.**
- **Arrive at 7:30-7:45am to help set up.**
- **Volunteers to help usher guests to break out sessions.**
- **Grant to run the Raffle**

- 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
 - Heather and Katie are both RD's, still need a patient rep.
 - * Athletics and Metabolic Diets –
 - *Sarah Marshall
 - *Maryam (VitaFlo)
 - *The Early Years – What to expect –
 - *need to find RD and patient rep (Melinda Halvorsen and Joanna Foreberg)
- Panel right at the end of the day
 - Grant – Moderator
 - Soo Shim – insurance assistance and Q&A. Will put together a stack of questions again. Shoebox with index cards.
 - Meredith Stutzman (Mom)
 - Alex Davis (Middle school)
 - Sean (college graduate)
 - Dr. Burton (**Danae to email for confirmation**).
- Luries Geneticist (Mindy Lee): Soo to invite her and Dr. Jones to the Annual Meeting.
- Dr. Flescher in Springfield: Shannon to find and invite her and her dietician.

- Also to invite Riley clinic in Indiana and clinics in St. Louis and Wisconsin.
- Illinois Department of Public Health has been invited every year (Doug) however has never been able to attend. **Maybe record a greeting from him and to give a few pieces of advice to play for the guests. Grant will give him a call.**
- **Soo Shim to give DSCC a call to invite them to the meeting. Have a table, speaking time, all free of cost (August Nash is main supervisor at Chicago office).**

J. Cookie Exchange

- 12/3 2pm at the Kowalczyk Household, Bartlett, IL. Elf on the shelf (only 30 minutes), Frozen, etc.
- Link is live on the website.
- Danae to bring hot chocolate.

K. PKU Press

- Change from Abbott to Ami's contact, not confirmed but actively pursuing. Can do it for a total of \$20-50.
- Section called Mary's corner.

L. Vendor Events or News

M. Hospital Update via Soo Shim:

- Teen day workshop complete! 12 Teens – Sean and Elena attended, clinic reports they did a fantastic job.
- Luries – Grocery store tour in lieu of the bootcamp.

IV. MISCELLANEOUS

- Mary's PKU ribbon fundraiser: Still at \$160