



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

PKU Organization of Illinois- Board Meeting

DATE: 9/20/17

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:

Melinda Halvorsen

Kim Kowalczyk

Matt Bartke

Danae Bartke

Grant Smith

Elena Caro

Andrea Bianculli-Hall

Call In:

Alex Seidler

Soo Shim

Shannon O-Brien

Mary Lonski

Hazel Vespa

Not Attended:

Ami Vanderhoof

Sean Haney

A. Officer Reports President's Report –

Discuss board members for next year. ALL POSITIONS MUST BE VOTED ON.
President: OPEN (role – over see all of the events, grant writing to all vendors, editor in chief of PKU press, organization of PKU annual meeting, sponsorships for the year, facilitating cooking classes with the vendors).

Vice President: Grant (over sees the outside community, the social media, add on instagram? in charge of family fund day)

Secretary: Kim (taking notes at meetings, emailing minutes to board)

Web Admin: OPEN (main page maintenance, add minutes to the website, set up SLACK)

Treasurer: OPEN (balance the budget on Quickbooks)

NPKUA rep: Kim (Minimum 2 year commitment, all NPKUA call in meetings, yearly in-person meeting (even-years at the national conference, odd-years in Washington D.C).

Add on separate positions: Vendor rep, PKU press editor in chief

At Large: Sean, Elena (interested in NPKUA), Ami

Honorary: Mary Lonski, Hazel

Clinics: Krista Engen, Soo Shim

Rolling off: Matt, Danae (will help with web site), Andrea (will help with wine tasting), Shannon O'Brien

Interested: Meredith Stutzman (at large), Marissa Pratcher (Treasurer?), Melissa Bernzen (NPKUA), Alex Seidler (on the phone today! Welcome!), Melinda and Eric Halvorson (At today's meeting, welcome!)

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.

- It does donations, websites, raffle, and silent auction, and constant contact for \$100/month. We are currently in a 2 month promo, will ask for a one month extension because it is taking a long time to get set up.

Website moved to GoDaddy. So much easier, and it still uses Wordpress.

Slack?? Can also call in every month for the meetings.

C. Treasurer's Report-

Taxes are done!

We have a credit card. Let's use it more.

D. Secretary's Report-

- GSI Outdoors wine tasting gift needs to be posted on 3 social media platforms as part of their contract for donations.

- Kim will email grant to post on social media
-

E. NPKUA Update –

Looking for anyone who would be interested in joining the NPKUA as an at large member to join their fundraising committee.

Patient registry now at 706

Healthcare in general is moving slowly, not just the MNEA. We just added two new co-sponsors, but we predict to add more in the next few months. NORD offered to help us in legislation.

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?

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. 32 people registered. Registration closes on the 4th. Usually over 60.
- Will use Gesture again, Pull-a-Cork.
- Donation item update – We are in good shape.
- Will send Grant a link once Gesture is live. Will have it live September 30th for people to start bidding.
- We will have Nutricia Pasta and Cambrooke pizza crust

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.
- Rachel Merz – Confirmed guest Chef. MUST hear back by October 1st. Andrea will email her.
- Hotel group discount ends 1 month before the event. Grant to send out an email to everyone regarding this (before Monday 9/25)
- 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. Britney is out of the Hospital until the 9/25, she will email us an agenda after her return.
- Andrea Aras genetic counselor to do the educational program. Researchers are volunteering.
- Margaret needs toaster oven to make "ready dough." Melinda and Andrea will bring theirs to the meeting.
- Mary to sell her ribbons at a table next to the T-shirt sale
- 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.
- Daelyn Richards has not responded to recent emails. 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, too look for an article regarding CRISPR to put into the registration folders. Adam Nelson's lab also working on CRISPR.
- Kim to include NPKUA article about grants that were awarded for PKU research
- 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 8/22/17
 - *Maryam (Vitaflo) em 8/22/17
 - *The Early Years – What to expect –
 - *need to find RD and patient rep (Melinda Halvorsen and Joanna Foreberg)
- Can do a panel right at the end of the day
 - Grant – Moderator

- Soo Shim – insurance assistance and Q&A
- Meredith Stutzman – Potential member, will get back to us later
- Alex Scioratta (Middle school) – confirmed.
- Elena (not confirmed, waiting on school schedule)
- Sean (confirmed) emailed 8.22.17

- Mission Possible theme
- Postcards mailed
- Luries Geneticist moved over to Rush may be able to bridge a gap. Danae will send an invite to our PKU meeting. Soo and everyone in the clinics will reach out to their colleagues about advertising this meeting.
- Illinois Department of Public Health has been invited every year (Doug) however has never been able to attend.

J. Cookie Exchange

- 12/3 2pm at the Kowalczyk Household, Bartlett, IL. Elf on the shelf (only 30 minutes), Frozen, etc.

K. PKU Press

- Change from Abbott to Ami's contact, not confirmed but actively pursuing. Shannon did not receive their copies, Soo did. Danae to contact Abbott about their tardiness to print and also their lack of shipment to the clinics.

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