



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

PKU Organization of Illinois- Board Meeting

DATE: 5/10/17

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
Sean Haney
Kim Kowalczyk

Call In:

Mary Lonski
Andrea Bianculli
Elena Caro
Soo Shim

Not Attended:

Ami Vanderhoof
Katie Pasciewicz
Hazel Vespa
Shannon OBrien

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-

Ami is getting caught up with quick books.

Grant gave check from Jumpzone to Danae' at today's meeting who will drop it off to Ami tomorrow.

D. Secretary's Report-

PKU Advocacy Summer Internship

Julie Fleischer is a new geneticist in Springfield. Kim will get contact info to Danae who will get in contact with Shannon about including her in our meetings.

Biomarin's "Proceeding from Kids to Adults" booklet to be mailed out to clinics soon.

Check to see if there is a link to this online.

E. NPKUA Update –

Attended Biomarin's Patient Advocacy Summit – Amazing – Lots of ideas

-Big sibling/Little sibling mentorship program (16-25 y/o paired with 10-16 y/o)

-PKU adult hotline for help to get back to a clinic. Kim will email Matt the link or webpage.

-Join forces with other Advocacy groups: Crohn's, CF, Celiac, eosinophilia etc

- PKU Adults want information to understand insurance coverage and lingo (annual meeting breakout session?) Soo Shim to speak about this?

-Patient authorization forms at our events that will consent to allow Biomarin to reach out as a care organization. No – Biomarin needs to have their own table with their own flyers.

-Elementary/high school low protein food drives to create emergency care packages, maybe Thanksgiving Care packages to families in need.

-Reach out to high school (NHS students) and college students to start their own fundraiser (food drive, 5K walk, chuck-a-puck, bake sale etc) in return for volunteer hours.

-Other ideas: March Madness 50/50 bracket to go to scholarship fund (college theme), Fantasy football league.

Make a list of volunteer ideas to post on PKU website.

Event idea – Teen dinner with no parents invited

Digital tips: Should be posting twice weekly

If people don't respond to emails, change the subject line and send the exact same email

Use memes to promote ideas or events.

Use Facebook Live for live event coverage.

Look into Google Grants – free media site to promote your cause. Takes three months to hear back, but you will get \$10,000/month worth of media space. The NPKUA uses this.

Everyone loves Dr. Burton! Everyone loves our PKU Press! Everyone loves our organization and looked to us A LOT as an example to follow!!!!

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
- 71 attendees so far – hoping for 80 people. Last year we were at 92. Emails to go out tomorrow, Monday and Tuesday/Wednesday
- Mexican theme: Cater from Chipotle. Danae would make the extra low protein food.
- Committee update?
- 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
- Flyer of list of volunteer events: “run your own summer event” and they will be featured in the fall PKU press Special Person’s column
- Keep PKU camp registration open on computer. Printed out flyers for Camp and Mongolian Grill
- Tents for food

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. PKU press into the bags
- Will need vendor tables.
- Cambrooke will be willing to do a waffle bar. Kim to refer Margaret’s email to Danae and Sean.
- We have a \$750 food stipend
- Possibly a Q&A session/panel. Danae and Ami to put together an agenda.
- Outreach to the clinics: Have them hand out flyers to their new families. Two of the UIC dieticians will be present. Katherine Engle, and Kristin Engen.
- Katie from Lurie’s has a shopping list to provide. Kim to email Danae to get in touch with Katie to get those shopping lists to put in the bags.
- Committee update? Kim emailed all vendors for in-kind donations on 5/6/17.
 - Vitaflo (Maryam) will have a table and Vitabites
 - Cambrooke (Margaret) will donate food, and inquired about waffles again?
 - HowMuchPhe (Sarah) can not donate books due to lack of resources, but can do packets with information about National PKU News, a \$5-off coupon for HowMuchPhe.org and magnets/tattoos as gift items. Wants to know where the majority of our PKU patients come from. Mostly western suburbs.
 - Mevalia (Aneta) No samples in the US, forwarding my email to the German headquarters but will likely not be able to make the deadline.
 - Biomarin (Michelle) Cutting boards, measuring cups, water bottles, pocket guides for baby food phe content
 - Kim to talk to Danae if no response from Mike.

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 first week of June
- 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' sent out a spreadsheet to keep track of donations – just general guidelines.

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.
- 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.
- Topic discussion for MNEA and the NPKUA in Washington DC
- Break out sessions (30 minutes): Dieticians to talk about the How Much Phe app, Heather Ricca to lead a session for maternal PKU, sports and PKU, Soo Shim to talk about insurance for young adults with PKU.
- Involving Ranetta Franco? Runs a non-profit called Compassion Works. She is an insurance consultant and very well versed in insurance and PKU advocacy. However she has a \$5,000 fee unless you have an NPKUA membership.
- 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.
- Mission Possible theme

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 PRESS DEADLINE: June 30th
- Highlight PKU volunteers and their events

L. Vendor Events or News

- The Proprietary Acidemia Foundation accepted our \$500 sponsorship, and will have our information out on a table
- Nutricia sponsoring a cooking event, Mike is reaching out to The PKU chef. Date unknown.

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.
- PKU board to email their reps, and to their loved ones to email their reps too
- Twitter – Mark Melancon. Danae will make it a jpeg and send to Grant to re-tweet!

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
- Flyer sent to Matt to be put on webpage
- 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

- Mary’s PKU ribbon fundraiser has raised \$145 so far! And still going!