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| **Staff liaison meeting** | | | | |
| **Date:** June 30, 2016 **Start Time:** 11:00PM CST **End Time:** 12:00PM CST | | | | |
| **Attendees:** Ellen Denzen, Jackie Foster, Christa Meyer, Lih-Wen Mau, Tammy Payton, Lensa Idossa, Kelsey Besse, Heather Moore, Jaime Preussler, Kristen Edsall, Heather James, Jill Randall, Stephanie Farnia, Beth Murphy  **Absent:** Linda Burns | | | | |
| **TOPIC** | **DISCUSSION**  **LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome and attendance | Kate | 3 min | Kate conducted roll call. |  |
| Updates on Web Page, and process for adding documents to the Web Page | Kate | 20 min | * The link is now live, and housed on [www.bethematchclinical.org](http://www.bethematchclinical.org) and click on the networks tab. Go to Research, and then research protocols. We are the Patient Centered Outcomes Research * The link has been sent out to the group * Send any documents that you want saved on the website to Kate. Kate will then upload them into the P drive folder, and Renee Ryan will upload them onto the website. * Once Kate receives the training, she will be uploading everything onto the website herself. * The website is not password protected, and is available to the public * Anything you do not want the public to see will need to be sent by email | * Ellen will ask if it is ok to include articles that we need to pay for on the website |
| Working Group Updates | All | 25 min | * **Physical health and fatigue—**prior to the kickoff meeting members were asked to provide what they already know about the physical health and fatigue area. The group is making a list of the gaps in research, and will discuss the general categories at the next meeting. They will break into sub groups to decide how to go about the literature reviews. Next meeting is July 6th. * **Patient, caregiver and family education and support—**the full group met on June 9th for the first time. They have had a couple smaller group meetings to discuss the literature review. They came up with about 80 articles, and will be conducting a first round of reviews to determine which are relevant and which are not. The next meeting is July 7th, and they will talk about a plan for the second round of literature reviews. * **Emotional, cognitive and social health—**there have been two group meetings on Friday mornings. There was one patient on the last call expressing concerns regarding the literature reviews, and the WG emphasized their role was more to bring the experience. There will be 3 subgroups, and assigning articles to the groups. Plan for the next meeting is to discuss the summaries as a large group. The next meeting is scheduled on July 29th. * **Models of care delivery-survivorship and late effects—**the co-chairs had an overarching question of what they want to cover. They haven’t formed sub groups as of yet. They have had challenges scheduling a follow up meeting. They will include Linda to provide more information on the next follow up call. There is a doodle poll out right now to schedule the WG kick-off meeting, and hope to schedule the meeting for early July. Ellen will ask Kristen and Stephanie if there is a payer to include in the group. * **Sexual health and relationships**—there was one person unable to attend the meeting on the date scheduled, and have removed themselves from the WG. The group is still looking for a couple extra members. The to-do list is to conduct a literature review. They broke down different topics, and each person picked a topic to do a literature review. The patients and caregivers will share their experiences rather than conduct a literature review. Next meeting is scheduled on July 7th. * **Financial burden—**First call was this week. They spoke with the co-chairs this morning to get the action steps down. Gloria Gee gave great information and background. Dr. Greg Abel did a presentation about a study he did, which looked at out of pocket costs. Talked about needing to look at long-term costs as well as short-term costs. Medical staff awareness about financial burden and costs was also discussed. They also talked about determining the actual costs of transplant, and how to better prepare them for the costs. They will send out questions to have the patients answer, and review on the next call. Next call is scheduled for July 26th. | * Make sure to invite the PORI WG calendar to all WG meetings |
| Q & A | All | 10 min | * Caregivers/patients can read articles to the extent that they feel comfortable, but do not need to conduct literature reviews * Make articles available to caregivers/patients if they are interested in providing reactions * It would be helpful to focus on quality review articles, and then scan through other articles * When sending out the NIH manuscript drafts, they are separated by WG. It would be best for the PCORI WG’s to read the manuscript draft which is closest to their WG * The deliverable for each WG is 1-2 pages. We are not requiring the WG’s to write a paper. We will have summary papers that everyone can contribute to * End goal: bullet list of gaps in research, and research questions that would work for comparative effectiveness research. We will propose this list at Symposium 2 in December. We will get feedback and reprioritize if necessary, and then work on the summary of recommendations |  |
| Wrap up, meeting schedule, action items | Kate | 2 min | Next meeting: August 25, 2016 |  |