



Rochester Epidemiology Project Community Advisory Board Meeting Notes September 8, 2016

In attendance - Board Members: Marie Cano, Ken Caron, Pete Kasper, Liz Morice, Joan Rose, Dee Servick, Harold Stewart, and Denny Uthke (8 attendees)

In attendance – REP Team: Walter Rocca, Jennifer St. Sauver, Lori Klein, and Robin Adams

The September 2016 meeting began with a discussion about the potential integration of the REP CAB with a Mayo Clinic Patient and Family Member Advisory Committee (PFAC) led by Dr. Joan Griffin (Scientific Director of the Care Experience Program in the Mayo Clinic Kern Center for the Science of Health Care Delivery). Joan works closely with many researchers who are looking for advice and input on their research studies from community members, patients, and family members. The PFAC has been offering feedback on a wide range of research studies; however, the committee is a small group of only Mayo Clinic patients and family members. Joan would like to get a larger variety of opinions and include community members. If the integration were to happen, it would mean that the interested members from PFAC would integrate with the CAB. We would change the name of the REP CAB to reflect that the merged group would be offering input on more than just REP studies. We may elect a co-chair from the PFAC to share responsibilities with Denny. We would continue to meet at the library with Robin coordinating details and Lori facilitating meetings. Here are two recent requests from researchers seeking input from PFAC members:

1. Review patient questionnaire and offer feedback about questions and advise of any information that the committee member feels is missing from the questionnaire.
2. Assist in developing a survey for caregivers that would collect information helpful to the doctor in knowing the caregiver's ability and willingness to help with their loved ones care.

During the discussion about potential integration, CAB members expressed some questions for Dr. Griffin and the PFAC:

- Are the PFAC members feeling “overwhelmed” by the number of studies they need to review? Is this why we are being invited to join...to help lessen the current burden on the PFAC members?
- Will the PFAC members feel comfortable with us? Will they feel like we are stepping on their toes?
- Will each, the CAB and the PFAC, feel allegiance to their original group? Concern about true integration - is it really possible to have both groups feel like they're one group after they are merged?
- How many people are in the PFAC and how long have they been in the group?

CAB members wrote in positive comments on the evaluation at the end of the meeting. At least half of the group at the 9/8/16 meeting expressed interest for integrating with the PFAC. Now the next step is for Lori to attend the 10/24/16 PFAC meeting to meet the members and better understand the role of their committee. After the 10/24/16 meeting, Dr. Griffin will meet with Lori and Jenny to discuss the feedback from both groups and determine whether or not to propose integration in 2017.

Next, Lori and board members provided updates starting with the work team. The media and events work team met briefly prior to the start of the CAB meeting and primarily discussed the Women's Expo. The booth will include the large pop-up banner, brochures (English and Spanish), bookmarks, pens, magnets, lip balm, and candy. The work team requested that the FAQ binder at the expo include answers to the questions on the pop-up banner (this is now complete). Attached with these notes via email are: FAQ document and Q & A for pop-up banner – both documents will be used for reference during the Women's Expo.

Then Walter updated the group on the REP's 50th anniversary celebration and site visit by our program officer from National Institute on Aging (NIA) held on September 26, 2016. The event has since happened and was a huge success. A small group of CAB members attended as well as 50+ other invited guests. We will provide a short update with pictures at the January 2017 meeting.

Next, Lori reviewed the 50th Anniversary activities and materials (the banner-ups and pop-up banner were displayed at the meeting for CAB members to view). Thank you to CAB members who volunteered in the booth at Thursdays on First and 3rd in June. And, thank you to the CAB members who are volunteering to help in the booth at the Mayo Clinic Cancer Education Center and Madonna Towers. A number of REP presentations are scheduled for October and outlined in an email from Lori dated 9/30/16.

Lastly, Walter provided an update and demonstration of the Data Exploration Portal. The REP is getting ready to launch a web tool called "Data Exploration Portal" via our external website. A limited explanation of the portal:

- Visitors will access the link to the portal by visiting our webpage at www.rochesterproject.org
- Visitors will be asked to register by providing their first & last name, company, city, state, country, intended use (research, clinical or general), email address, password and then agree (or not) to receiving emails and to the terms and conditions
- Once the portal is accessed, visitors will choose 2 diseases for which they would like to see a correlation
- Results will include multiple graphs showing the correlation
- A study could not/should not be published by using the portal info exclusively; rather the info may simply generate questions a researcher may want to study

Walter demonstrated several different correlations during the meeting and demonstrated correlations suggested by CAB members. The portal is still in the development stage, but we hope to release it to the public in the next 3-6 months.

NEXT MEETING: Thursday, **January 12, 2017** at **5:30pm** at the **Rochester Public Library**.