

Board of Governors Meeting via Teleconference / Webinar

Tuesday, May 22, 2018

12:00 pm – 1:30 pm ET

Board Members Present:

Debra Barksdale, PhD, RN; Larry Becker; Francis Chesley, Jr., MD (representing Gopal Khanna); Francis Collins, MD, PhD; Allen Douma, MD; Alicia Fernandez, MD; Leah Hole-Marshall, JD; Russell Howerton, MD; Gail Hunt; Barbara McNeil, MD, PhD; Ellen Sigal, PhD; Kathleen Troeger, MPH; Robert Zwolak, MD, PhD

Board Members Absent:

Grayson Norquist, MD, MSPH, *Chairperson*; Kerry Barnett, JD, *Vice Chairperson*; Christine Goertz, DC, PhD; Harlan Krumholz, MD, SM; Richard Kuntz, MD, MSc; Freda Lewis-Hall, MD; Sharon Levine, MD

MINUTES

Agenda Item	PCORI Speakers
Call to Order, Roll Call, and Welcome - <i>Larry Becker, Chair, Finance and Administration Committee (FAC)</i>	Mr. Becker chaired and opened the meeting, welcomed all to the meeting of the PCORI Board of Governors and read the Chair Statement on Conflict of Interest.
Consider for Approval: Consent Agenda - Minutes of the April 30, 2018 Board Meeting - Nomination of Co-Chair for the Advisory Panel on Rare Disease (RDAP) - <i>Larry Becker</i>	Mr. Becker introduced the Consent Agenda which included the approval of the April 30, 2018 meeting minutes and the nomination of Cindy Luxhoj, MUP to serve as Co-Chair of the Rare Disease Advisory Panel (RDAP) through August 2020. Mr. Becker gave the opportunity to Board members to discuss any of the matters on the Consent Agenda. No separate discussion was requested. The following motion was made by Kathleen Troeger and seconded by Russell Howerton: Motion: Approve each of the motions on the Consent Agenda as reflected below: - Minutes from the April 30, 2018 Board Meeting - Nomination of Cindy Luxhoj, MUP as Co-Chair for the Rare Disease Advisory Panel (RDAP) to serve until August 31, 2020. <i>The Board approved the minutes of the April 30, 2018 Board meeting by a majority vote of the Board by voice vote (no opposed; no abstentions); the Board in a separate vote approved the nomination of Cindy Luxhoj, MUP as Co-Chair for the Rare Disease Advisory Panel by a majority vote of the Board by voice vote (no opposed; no abstentions).</i>

Consider for Approval: Revisions to the Delegation of Authority and Expenditure Approval Policy - Regina Yan, MA, Chief Operating Officer	Regina Yan provided an overview of the proposed changes to the <i>Delegation of Authority and Expenditure Approval Policy</i>, approved by the PCORI Board of Governors on September 27, 2016 to reflect the evolution of the positions, titles, and roles of PCORI's executive staff. Larry Becker, Chair of the Finance and Administration Committee (FAC) confirmed that the FAC reviewed the proposed revisions to the Policy at its meeting on March 20, 2018 and recommends that the PCORI Board amend the <i>Delegation of Authority and Expenditure Approval Policy</i> to include the proposed revisions. There were no questions regarding the proposed changes. The following motion was made by Alicia Fernandez and seconded by Debra Barksdale Motion: <i>Approve proposed revisions to the Delegation of Authority and Expenditure Approval Policy by a majority vote of the Board by voice vote (no opposed; no abstentions).</i>
Review of Q2 FY-2018 Dashboard - Joe Selby, MD, MPH	Dr. Selby presented the Q2-2018 Dashboard for the Board's review. The Dashboard demonstrated 5 green-flagged items (items that are on track) and 3 yellow-flagged items (items that are off target by more than 10%-15%, depending on the metric). The five metrics that are green are project performance, research using PCORnet, PCORI abstracts posted to the website, results published in the literature, and Altmetric (attention to PCORI research). The metric for Funds Committed to Research is yellow because PCORI did not commit funds to research in Q2, in part due to a much smaller than expected slate for low back pain research. The metric for Expenses is yellow because expenses were below the goal of 85% of the budgeted amount. The metric for PCORI Peer Review is yellow because early data show that the process is taking longer to complete than the established target. Dr. Selby noted that the more in-depth view of these data, rather than a quarterly view, indicates improvements in time for completion of PCORI Peer Review. There were no red-flagged items (items that are off-target and in need of attention or action by the Board). Dr. Selby presented examples of results on three of PCORI's goals: to increase information, to speed uptake, and to influence research. To illustrate increasing information, he shared that as of Q2, 52 CER projects have had their primary results peer-reviewed and are publicly available. He highlighted published results from a PCORI-funded research study of peripheral artery disease (PAD) that found that a

	home-based exercise intervention with a wearable activity monitor and telephone coaching did not improve walking performance compared with usual care. This publication had a high Altmetric score (a measure of attention). To provide an example of uptake of study results, Dr. Selby shared that results of PCORI-funded studies have been cited in evidence-based clinical recommendations, including in UpToDate®, DynaMed Plus™, and other evidence-based clinical recommendations. He shared that PCORI is credited with inspiring the revision of courses to support patient-centered multidisciplinary research, and the creation of a Citizen Scientist program at the University of Florida’s Clinical and Translational Science Institute. Board Members expressed interest in seeing a full list of CER results from PCORI-funded studies, and a full list of studies underway in PCORnet. It was suggested that the Dashboard have an indication of which yellow-flagged items have been yellow for multiple quarters. The Board discussed the challenges of funding research in low back pain, and discussed how to evaluate uptake of PCORI findings compared with other funders.
People-Centered Research Foundation (PCRF) Update - <i>Kathy Hudson, PhD, Executive Director, People-Centered Research Foundation (PCRF)</i>	Dr. Selby introduced Dr. Kathy Hudson to the Board. He noted that today’s presentation was in response to a Board request for an “elevator speech” to clarify the relationships between, PCORI, PCRF and PCORnet. Dr. Hudson explained that PCORnet is a large national clinical research network that is independent from, but was developed with funding from, PCORI. She also noted that PCRF is a nonprofit charitable organization created by network leaders participating in PCORnet to ensure long-term sustainability of PCORnet. She also described how PCRF is leading PCORnet through an evolution to ensure that all parts of the network are committed and able to conduct patient-centered studies supported by a range of public and private research funders. Following the presentation, the Board discussed PCRF’s future plans for business development, stakeholder engagement, and network membership. Dr. Hudson explained that PCRF is in the final stages of a competitive network membership application and review process. She also discussed PCRF’s focus on developing a robust business plan and financial forecast. The Board expressed interest in receiving updates this summer as PCRF develops the business plan. The Board discussed PCRF’s intended early emphasis on studies involving heart and mind conditions. Dr. Hudson

	noted that developing core capabilities in data, clinical trials, and engagement in those specific therapeutic areas may give PCORnet a competitive advantage. The Board also discussed clinician engagement in PCORnet studies. Dr. Selby explained that PCORnet is trying to effect cultural change, wherein clinicians come to understand that PCORnet exists and can raise research questions and participate in research projects. The Board expressed interest in discussing clinician engagement plans further at an upcoming Research Transformation Committee. The Board also expressed interest in learning about industry-funded studies being conducted in PCORnet.
Wrap up and Adjournment - <i>Larry Becker</i>	Meeting ended at 1:25 pm

Minutes were approved by the PCORI Board of Governors 06-19-2018