

**BOARD OF GOVERNORS MEETING
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
MAY 16, 2011
1:00 P.M.**

PUBLIC MEETING

IN ATTENDANCE: PCORI Board - Eugene Washington (Chair), Steve Lipstein (Vice Chair), Kerry Barnett, Lawrence Becker, Francis Collins, Arnold Epstein, Christine Goertz, Leah Hole-Curry, Gail Hunt, Robert Jesse, Harlan Krumholz, Richard Kuntz, Freda Lewis-Hall, Ellen Sigal, Harlan Weisman, Robert Zwolak. **Methodology Committee** - Sherine Gabriel (Chair), Sharon-Lise Normand (Vice Chair), Naomi Aronson, Ethan Basch, Michael Lauer, Brian Mittman, Sebastian Schneeweiss, Jean Slutsky.

GUESTS: Joe Selby (incoming Executive Director), Pat Nichols (TMC), Laura Skoff (TMC), Shar'on Barclay (TMC), Gail Shearer (TMC), Lauren Greco (TMC), Wanita Thompson (Trissential), Jane Van Dervoort (Trissential), Lane Bailey (GolinHarris), Matt Bennett (GolinHarris), Joe Clayton (GolinHarris), Richard Schmitz (GolinHarris).

PARTICIPATING VIA PHONE: Allen Douma.

ABSENT: Debra Barksdale, Grayson Norquist, Carolyn Clancy (represented by Jean Slutsky)

1. CALL TO ORDER

Mr. Washington called the meeting to order at 1:05p.m. and welcomed those in attendance and reminded all that the meeting was being webcast live. He began by introducing Mr. Joe Selby, the incoming Executive Director.

2. APPROVAL OF MINUTES (3/7/11-3/8/11)

Action: There was a motion and second to approve the Minutes; approved.

3. MISSION STATEMENT and LOGO

Mr. Joe Clayton of GolinHarris led a presentation on developing the PCORI mission statement and brand, including logo. He identified the objectives of PCORI's mission statement, which is to serve as a guide for the organization and capture PCORI's commitment to patients, providers and the health care delivery system.

Mr. Washington noted that the goal is to approve a mission statement at the July board meeting. He invited the public to send comments and suggestions to be incorporated into the process.

4. PROGRAM DEVELOPMENT COMMITTEE REPORT

Mr. Kuntz reported that the committee's priorities are to begin a landscape review and initiate a process for the tier one grants, and that a project manager has been retained to support the committee. The committee is working closely with The Lewin Group to understand how to shape the agenda and landscape review. The focus is on outlining the research agenda and the national priorities. The committee has begun to define the project strategy by relying on characteristics defined by the statute.

Mr. Washington recessed the meeting until 3:15pm.

5. PUBLIC COMMENTS

- A. Elaine Larson, Columbia University, School of Nursing
- B. David Shahianof Society for Thoracic Surgeons
- C. Sharon Smith of National Trauma Institute
- D. Seth Ginsburg of Global Healthy Living Foundation
- E. Peter Pitts of Center for Medicine and Public Interest
- F. Alexander Lloyd of Healthcare Chaplaincy
- G. DolphChianchiano of National Kidney Foundation
- H. Delores Rogers (Affiliation Unknown)
- I. Laura Newman of Patient POV
- J. Tom Caruso of Biomedical Informatics Think Tank

Mr. Washington encouraged others who were listening or watching the live webcast to submit comments via our website.

6. METHODOLOGY COMMITTEE REPORT

Ms. Gabriel reported that the committee has two key deliverables: methodological standards for research and a translation table. The committee is requesting Board approval of the charter and outlined the next steps of refining the working definition. Ms. Gabriel stated that the working definition is a high-level definition that puts the patient's voice in the center. It includes characteristics on how to operationalize the definition of PCOR. The next steps are to: adopt the definition to guide future work, invite detailed input from the board and stakeholders, synthesize input and revise, and bring back to the board for final approval. The work plan is under development.

Action: There was a motion and second to approve the Charter; approved.

7. ADJOURNMENT

The meeting adjourned at 5:15p.m.

BOARD OF GOVERNORS MEETING
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
MAY 17, 2011
8:30 A.M.

PUBLIC MEETING

IN ATTENDANCE: PCORI Board - Eugene Washington (Chair), Steve Lipstein (Vice Chair), Kerry Barnett, Lawrence Becker, Francis Collins, Arnold Epstein, Christine Goertz, Leah Hole-Curry, Gail Hunt, Robert Jesse, Harlan Krumholz, Richard Kuntz, Freda Lewis-Hall, Ellen Sigal, Harlan Weisman, Robert Zwolak. **Methodology Committee** - Sherine Gabriel (Chair), Sharon-Lise Normand (Vice Chair), Naomi Aronson, Ethan Basch, Michael Lauer, Brian Mittman, Sebastian Schneeweiss, Jean Slutsky, Clyde Yancy.

GUESTS: Joe Selby (incoming Executive Director), Pat Nichols (TMC), Bill Hubbard (TMC), Laura Skoff (TMC), Shar'on Barclay (TMC), Gail Shearer (TMC), Lauren Greco (TMC), Wanita Thompson (Trisential), Jane Van Dervoort (Trisential), Joe Clayton (GolinHarris), Richard Schmitz (GolinHarris).

PARTICIPATING VIA PHONE: Allen Douma.

ABSENT: Debra Barksdale, Grayson Norquist, Carolyn Clancy (represented by Jean Slutsky)

1. CALL TO ORDER

Dr. Washington called the meeting to order at 8:08a.m. and welcomed the public attendees. He reminded all that the meeting was being webcast live.

2. FINANCE & ADMINISTRATION COMMITTEE REPORT

Mr. Barnett reported on the conflicts of interest policy stating that it applies to board, committees, and staff. The policy has been through extensive review and revisions to address concerns related to federal employees. The policy follows the clear requirements of the statute and prohibits gifts. The incoming Executive Director may require more stringent requirements for staff. Mr. Barnett noted that the conflict of interest policy for third parties – vendors, peer reviewers, grantees, consultants, etc. – is underway and would be presented at a future board meeting. Board members are encouraged to submit examples or models.

Action: There was a motion and second to approve the proposed Conflict of Interest Policy; approved.

Mr. Barnett reviewed highlights of the proposed budget, indicating that the numbers included for the Methodology Committee were placeholders and would be refined by that group in the near future. He indicated that the committee will continue review the financial statements on a monthly basis and regularly review expenses and variances with the staff.

Action: There was a motion and second to approve the 2011 Budget; approved.

Mr. Barnett continued his report with a review of the April 2011 financials. PCORI is ahead of budget as activities are still starting up. The committee will be working with Mr. Selby on staffing structure, the employment policies, benefits and office location. In addition, there will be a review of the board compensation policy based on the data collected for actual time spent on PCORI activities. Mr. Barnett noted that the bylaws will expire soon and the committee will be looking at what may need to be revised. Today, the committee is asking for approval in extending the current bylaws.

Action: There was a motion and second to approve extension of the current bylaws until the end of the calendar year; approved.

3. PUBLIC COMMENTS

- A. Tony Coelho of Partnership to Improve Patient Care
- B. Angela Ostrom of Epilepsy Foundation
- C. David Cloud of National Sleep Foundation
- D. Kathy Wyrwick of United Biosource Corporation
- E. Ann Marie Lynch of Advanced Medical Technology Association (AdvaMed)
- F. John Santa of Consumers Union
- G. Dawn Sabio of Washington University

Mr. Washington encouraged others who were listening or watching the live webcast to submit comments via our website. He recessed the meeting until 10:15a.m.

4. COMMUNICATION, OUTREACH & ENGAGEMENT COMMITTEE REPORT

Ms. Levine reported the committee is recommending a name change to better reflect the responsibilities and scope of work.

Action: There was a motion and second to approve the committee's name to Communication, Outreach and Engagement Committee; approved.

Ms. Levine stated that the committee has been responded to many speaking requests. PCORI has presented to the American Medical Association, American Heart Association, American Association for Cancer Research, and InHealth. There are many pending engagements for the remainder of the year; mostly introductory in nature at this stage. Great effort is going into trying to expand the

board member and methodology committee member engagement through present connections and affiliations of individual board members. GolinHarris has put together an outreach plan for the executive director, helping Mr. Selby to become the primary external face for PCORI. Mr. Washington and Mr. Lipstein have been meeting with congressional leaders to keep them apprised of the progress. More outreach to the policy community is planned. PCORI has had two successful stakeholder forums and listening sessions, in St. Louis and New York. The thought is to take board members on the road for sessions apart from those held in connection to the board meetings. The July meeting in Washington, D.C. is a prime opportunity to engage with stakeholders and policymakers.

5. ADJOURNMENT

The meeting adjourned at 11:22a.m.