BOARD OF GOVERNORS MEETING
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)
NOVEMBER 23, 2010
9:00 A.M.

PUBLIC MEETING

IN ATTENDANCE: Eugene Washington (Chair), Steve Lipstein (Vice Chair), Debra Barksdale, Kerry Barnett, Lawrence Becker, Carolyn Clancy, Francis Collins, Allen Douma, Arnold Epstein, Christine Goertz, Leah Hole-Curry, Robert Jesse, Harlan Krumholz, Richard Kuntz, Sharon Levine, Freda Lewis-Hall, Grayson Norquist, Ellen Sigal, Harlan Weisman, Robert Zwolak.

GUESTS: Pat Nichols (TMC), Laura Skoff (TMC), Shar'on Barclay (TMC), Jackie Eder van Hook (TMC), Patrick McCabe (GYMR), Becky Watt Knight (GYMR), Art Herold (Webster, Chamberlain & Bean), Bill Hubbard (Consultant) and General Public.

ABSENT: Gail Hunt

1. **CALL TO ORDER**

   Dr. Washington welcomed everyone and called the meeting to order at 9:01am.

2. **ORGANIZATIONAL MATTERS**

   A. Ms. Hole-Curry led the discussion on the Articles of Incorporation.
   Action: There was a motion and second to approve the Articles of Incorporation; approved.

   B. Dr. Washington lead the discussion of the initial Bylaws that shall be reviewed and revised by the Board, as needed, in six (6) months.
   Action: There was a motion and second to approve the Bylaws with change; approved.

   C. The Consent Agenda was reviewed.
      1. Reaffirm designation of Chairman and Vice Chairman as officers
      2. Reaffirm banking resolution
      3. Affirm authorization to pay expenses to organize the corporation
      4. Affirm authorization to execute and file documents necessary in local jurisdictions
      5. Affirm authorizations to file tax exemptions
      6. Affirm authorizations to execute legal agreements
      7. Affirm authorizations to effect these resolutions
      8. Reaffirm hiring of Webster, Chamberlain & Bean (law firm)
      9. Affirm hiring of Larson Allen (outsource accountants—not auditors)

10. Affirm hiring of Transition Management Consulting (interim management) and GYMR (communications)

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

3. BOARD DISCUSSION: MOVING PCORI FORWARD

A. Dr. Washington began discussion by posing a series of questions about PCORI's stakeholders: While to some degree the stakeholders are defined by the authorizing legislation, how might PCORI better define the stakeholders? What other constituencies should PCORI consider? How might PCORI communicate with the stakeholders? The board then discussed these.

B. Dr. Washington then posed a series of questions about how PCORI should build on the work of others: How might PCORI go about an assessment? What is known about sources of existing research? What is known about research gaps? What kinds of gaps might exist? How might PCORI aggregate and expand upon existing research? The board then discussed these.

C. Dr. Washington summarized the morning's discussion as having identified the need for: 1) a taxonomy; 2) an environmental scan and surveillance of the landscape; 3) the identification of gaps in diseases, geographies, populations; and 4) definition of PCORI's role (convening, coordinating, collaborating, creating, and/or communicating. In advancing activities related to Patient-Centered Outcomes Research and its effective dissemination and use. These activities will be assigned to the Program Development Committee.

THE MEETING RECESSED FOR LUNCH AT 12:00 p.m.

The Board reconvened at 1:05 p.m.

4. WORK PLAN DISCUSSION

Mr. Lipstein presided and began by stating that PCORI's first report is due to Congress April 1, 2011. Prior to this first report, PCORI will address the following key deliverables:

A. Finance and Administration
1. Formulate annual operating budget
2. Establish compensation policies and procedures
3. Establish staffing plan
4. Establish organizational policies and procedures (e.g. conflict of interest, whistle blower, etc.)
5. Assess fiscal year end and audit schedule

B. Executive Director search
1. Retain search firm

2. Develop position specification and submit to Board for approval
3. Screen initial candidates and develop short list for Board

C. Program Development
1. Develop taxonomy to help standardize nomenclature
2. Initiate environmental scan and begin process of "gap analysis"
3. With Board, iterate assessment criteria to help build a framework for future PCORI work and some short-term illustrative projects.

D. Public Affairs and Communications
1. Based on Board definitions of PCORI success, mission, vision, and values, develop short-term positioning and messaging strategy
2. Develop initial website with features for public outreach
3. Establish two-way communication plan (inbound information to be solicited and received by the Board as well as outbound information to be shared by the Board with patients and other stakeholder groups)
4. Formulate media guidelines

E. Methodology
1. Develop Draft Charter for Methodology Committee (to include areas of responsibility, definition of working relationship and interface with Board)
2. Establish interface between Board and Committee

5. PUBLIC COMMENTS

Dr. Washington opened the public comment period at 2 p.m.

A. Katie Orrico of American Association of Neurological Surgeons and the Partnership to Improve Patient Care (PIPC) commented that an article by PIPC chair Tony Coelho was recently published in *Health Affairs.* In supporting CER, he makes three main points: 1) ensure transparency and opportunities for public input; 2) engage stakeholders proactively; and 3) recognize individual patient differences.

B. Douglas Kamerow, of RTI International, a family physician, suggested that the Agency for Healthcare Research and Quality's (AHRQ) clinical practice guidelines on pressure ulcers might be a good example of early victories; a model that would build support and momentum for PCORI's work.

C. Eric Gascho of National Health Council stated that his organization is the nation's leading voice for people with chronic diseases. Their member groups are a tremendous source of information and he offered PCORI the opportunity to turn to the various groups for assistance and input.

D. Andrew Sperling of National Alliance on Mental Illness commented that he is hearing a recurring theme of involving patient organizations in every aspect of PCORI's work. Encouragement should be focused on big questions such as treatment adherence, that can better inform the real world setting of

healthcare.

E. Kitty Werner of National Organization of Nurse Practitioner Faculties (NONPF) commented that they provide leadership and education for nurse practitioners. Their perspective is important; NONPF can be a resource to PCORI.

6. ADJOURNMENT

Dr. Washington thanked the board, staff, and public for attending the meeting. The meeting was adjourned at 2:15 p.m.