

CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

July 20, 2010

Gene L. Dodaro
Acting Comptroller General
Government Accountability Office
441 G Street, NW
Washington, D.C. 20548

Attention: PCORI Board of Governors

Dear Mr. Dodaro:

The undersigned organizations, representing cancer patients, providers, and researchers, are pleased to endorse the nominations of Ellen L. Stovall, Patricia Ganz MD, and Peter Bach MD to serve on the Board of Governors of the Patient-Centered Outcomes Research Institute (PCORI). Research related to the prevention, diagnosis, treatment, management, and monitoring of cancer will clearly be a major focus for the Institute, and it is essential that the Board of Governors include individuals who have the special expertise to advise on cancer-related topics while also providing appropriate guidance about the entire Institute research portfolio.

One in two men and one in three women in the United States will experience some form of cancer in their lifetimes. Approximately 1.5 million Americans will be diagnosed with cancer this year, and 11 million Americans are living after a diagnosis of cancer. In short, cancer touches the lives of every American family. Moreover, cancer represents a significant burden in terms of cancer care expenditures from public and private health systems and expenditures by cancer patients and their families for their care. There are critical questions about the optimal means of preventing, diagnosing, and treating cancer and about the outcomes and clinical effectiveness of cancer treatments, services, and items, all of which are core issues for consideration by the Institute.

We are writing to express our strong support for Ms. Stovall and Drs. Ganz and Bach, all nominated to serve on the Board of Governors of the PCORI. Their qualifications, in terms of expertise and experience, are complementary, and we recommend that all be named to the Institute Board of Governors in order to guarantee that the panel has the necessary depth of knowledge and direct experience related to cancer care.

Ellen L. Stovall

Ellen L. Stovall has been a leader in the effort to change the definitions of “cancer patient” and “cancer survivor” in order to ensure that those diagnosed with cancer receive high quality care through all stages of cancer, from diagnosis through active treatment to survivorship monitoring and care. The change in definitions has been accompanied by a change in health care providers’ approach to cancer patients and the involvement of patients in their care.

Ms. Stovall, currently the Senior Health Policy Advisor to the National Coalition for Cancer Survivorship, served as President and Chief Executive Officer of that organization for 17 years. She has provided long-term service on the Institute of Medicine (IOM) National Cancer Policy Board and its successor, the National Cancer Policy Forum. As a member of those organizations, she participated in the preparation of a series of reports that chronicled the strengths and weaknesses of cancer care in the United States and recommended reforms to achieve higher quality. She co-edited the IOM report on the issues facing adult cancer survivors, *From Cancer Patient to Cancer Survivor: Lost in Transition*.

In addition to long-term and intensive service in connection with cancer-related quality improvement initiatives, Ms. Stovall has experience related to quality efforts that reach beyond cancer. She has served as a member of the Boards of Directors of the National Committee for Quality Assurance and Leapfrog Group and has advised the National Quality Forum on cancer care quality measures.

Patricia Ganz, MD

Dr. Ganz, who has led several large clinical intervention trials in breast cancer, is currently engaged in research on the late effects of cancer treatment and improving the quality of care for cancer survivors. As Professor of Health Services in the School of Public Health and Professor of Medicine in the David Geffen School of Medicine at UCLA, Dr. Ganz has been at the forefront of efforts to understand the problems that confront cancer survivors after active treatment is completed and to improve the quality of care and quality of life for cancer survivors.

Through the UCLA-LIVESTRONG Survivorship Center of Excellence, Dr. Ganz has been able to put the results of her own research on survivorship and the research of others into place to address the needs of cancer survivors.

Dr. Ganz is Associate Editor of the *Journal of Clinical Oncology* and the *Journal of the National Cancer Institute* and is a member of the editorial board of the Cochrane Breast Cancer Group. In 1999, Dr. Ganz was named an American Cancer Society Clinical Research Professor and in 2007 became a member of the Institute of Medicine.

Peter Bach, MD, MAPP

Dr. Bach, Attending Physician at Memorial Sloan-Kettering Cancer Center, has broad experience in healthcare policy. His research has focused on racial disparities in cancer care quality, quality of care in Medicare, and cancer screening recommendations. Dr. Bach has written on the fragmentation of care in Medicare and has also reported that blacks do not receive lung cancer care comparable to the care received by whites diagnosed with lung cancer. His lung cancer prediction models have been used to reach conclusions about the benefits and risks of CT screening for lung cancer.

Dr. Bach served as Senior Adviser to the Administrator of the Centers for Medicare & Medicaid Services (CMS) and also serves on several national committees that are engaged in quality improvement. These include the IOM National Cancer Policy Forum and the Committee on Performance Measurement of the National Committee on Quality Assurance.

We look forward to the appointment of Ms. Stovall, Dr. Ganz, and Dr. Bach to the Patient-Centered Outcomes Research Institute Board of Governors. There is a pressing need for Board Members with significant experience in cancer care, cancer quality improvement, and healthcare policy. These three have that expertise and also have the ability to provide advice on matters that go beyond cancer and cancer care.

Thank you in advance for careful consideration of our recommendation of these three Board nominees.

Sincerely,

Cancer Leadership Council

American Cancer Society Cancer Action Network
American Society of Clinical Oncology
Bladder Cancer Advocacy Network
Breast Cancer Network of Strength
Cancer Support Community
The Children's Cause for Cancer Advocacy
Coalition of Cancer Cooperative Groups
International Myeloma Foundation
Lance Armstrong Foundation
The Leukemia & Lymphoma Society
Lymphoma Research Foundation
Multiple Myeloma Research Foundation
National Coalition for Cancer Survivorship
National Comprehensive Cancer Network
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Prevent Cancer Foundation
Sarcoma Foundation of America
Susan G. Komen for the Cure Advocacy Alliance
Us TOO International Prostate Cancer Education and Support Network