The Hon. Kathleen Sebelius Secretary of Health and Human Services 200 Independence Avenue, SW Washington, DC 20201

April 8, 2013

Dear Secretary Sebelius,

We are writing on behalf of the undersigned organizations with regard to the upcoming appointment of a new director for the Agency for Healthcare Research and Quality (AHRQ). We would like to take this opportunity to commend Dr. Carolyn Clancy for her decade of service as AHRQ director and to thank her for her commitment to evidence-based policies and patient-centered care.

Under the Affordable Care Act, the federal government has strengthened its commitment to a healthcare system that places the patient at the center of both research and care. New initiatives such as the Patient-Centered Outcomes Research Institute (PCORI) advance the role of the patient and advocate not only as participants but as active stakeholders and decision-makers for their own care and that of their loved ones. AHRQ will continue to play a critical role in ensuring that patient perspectives are given full consideration, both through the appointment of members to bodies such as the U.S. Preventive Services Task Force (USPSTF) and through coordination of crucial population health surveys that serve as the basis for future programs and policy decisions.

As you consider the appointment of a new director for AHRQ, we would urge you to select a candidate who not only possesses superb technical qualifications for this critical position, but who has also demonstrated a commitment to recognizing the diversity, perspective, and participation of patients in every decision the agency makes. We are confident that such an individual would encourage appointment of members to the USPSTF and other panels who share that commitment to prioritizing patients. We strongly believe that a healthcare system that actively learns from and responds to the voices of patients will be most effective in delivering high-value care. Thank you for your consideration on this most important decision.

If you have any questions, please feel free to contact Brandon Leonard, Program Manager at Men's Health Network, at brandonl@menshealthnetwork.net or 202-543-6461, ext. 101.

Sincerely,

Alliance for Aging Research Alpha-1 Association Alpha-1 Foundation American Cancer Society Cancer Action Network Blue Ribbon Advocacy Alliance Caregiver Action Network

Children's Tumor Foundation

COPD Foundation

Friends of Cancer Research

Health HIV

Hemophilia Federation of America

International Myeloma Foundation

International Pemphigus & Pemphigoid Foundation

Large Urology Group Practice Association

Moebius Syndrome Foundation

National Kidney Foundation

National Patient Advocate Foundation

NORD, National Organization for Rare Disorders

Oxalosis & Hyperoxaluria Foundation

Prostate Cancer Roundtable

Ed Randall's Fans for the Cure

Malecare

Men's Health Network

National Alliance of State Prostate Cancer Coalitions

Prostate Cancer Foundation

Prostate Cancer International

Prostate Conditions Education Council

Prostate Health Education Network

The Prostate Net

Us-TOO

Women against Prostate Cancer

Zero

RetireSafe

Society for Women's Health Research

The AIDS Institute

Tuberous Sclerosis Alliance

WomenHeart