

February 3, 2009

The Honorable Daniel Inouye, Chairman  
The Honorable Thad Cochran, Ranking Member  
Committee on Appropriations  
The Capitol, S-131  
Washington, DC 20510

The Honorable Tom Harkin, Chairman  
The Honorable Arlen Specter, Ranking Member  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
131 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Frank Lautenberg  
324 Hart Senate Office Building  
Washington, DC 20510

Dear Chairman Inouye, Ranking Member Cochran, Chairman Harkin, Ranking Member Specter and Senator Lautenberg:

We are writing to commend you for your leadership in improving the comparative effectiveness research (CER) language in the Senate's economic stimulus bill. We look forward to continuing to work with you as this package moves forward. The changes incorporated are of vital importance to patients and providers and will help ensure that government-supported CER is centered on improving the quality of patient care and empowering provider and patient decision making.

Specifically, we strongly support the improvements in the Senate bill and accompanying report language that focuses CER on comparative clinical effectiveness, and protects against the use of CER to deny access to care solely based on cost. It is important for patients and health care providers to have this sort of clinically-based information to better inform decision making and improve care. The adjustments made ensure that CER will focus on medical outcomes and contain the flexibility to take into account variations among different patient populations. We need a better understanding on how differences in genetics, race, sex, ethnicity, age, co-morbidities, nutrition, and other treatments impact clinical outcomes. As you move toward passage of a final bill, we would like to work with you to ensure the improvements you secured will be a part of it.

We deeply appreciate your commitment to make sure that CER is conducted and used in ways that are centered on improving patient care. We believe this goal could be further advanced by clarifying provisions that require openness and transparency. Patients and providers should have representation in setting priorities, conducting research and communicating results in each step of the process. This provision would be consistent with the broad goal of transparency and accountability in the use of funds under the economic stimulus bill, and will help ensure that

research is credible and relevant to patient and provider information needs. As further opportunities arise to advance these concepts, we would appreciate the opportunity to work with you to address it.

Again, we strongly support your leadership to seek improvements to the CER section of the Senate bill and report language, which represent a major step forward on behalf of patients and providers. We look forward to continued work with you on creating a CER system that ensures patients have access to necessary treatments and the tools required to make good health care decisions.

Thank you for your continued consideration.

Sincerely,

Alliance for Aging Research  
The AIDS Institute  
Alliance for Patient Access  
Alpha-1 Association  
Alpha-1 Foundation  
The Alzheimer's Drug Discovery Foundation  
American Association for Cancer Research  
American Association of Neurological Surgeons  
American Association of Orthopaedic Surgeons  
American Association of People with Disabilities  
American Autoimmune Related Diseases Association  
American College of Cardiology (ACC)  
American Urological Association  
Association of Clinical Research Organizations (ACRO)  
Association of Reproductive Health Professionals  
Californians for Cures  
Celiac Disease Center at Columbia University  
Coalition of State Rheumatology Organizations  
Colon Cancer Alliance  
C3: Colorectal Cancer Coalition  
Congress of Neurological Surgeons  
COPD Foundation  
Easter Seals  
Friends of Cancer Research  
Interamerican College of Physicians & Surgeons  
International Cancer Advocacy Network (ICAN)  
International Myeloma Foundation and Prostate Cancer International, Inc.  
Kidney Cancer Association  
Malecare Cancer Support  
Men's Health Network  
National Alliance on Mental Illness  
National Alliance for Caregiving  
National Kidney Foundation

National Foundation for Ectodermal Dysplasias  
National Alliance for Hispanic Health  
National Hemophilia Foundation  
National Hispanic Health Foundation  
National Hispanic Medical Association  
Plasma Protein Therapeutics Association  
RetireSafe  
Society for Women's Health Research  
Tuberous Sclerosis Alliance  
United Spinal Association  
Us TOO International Prostate Cancer Education and Support Network  
VHL Family Alliance  
Virginia Prostate Cancer Coalition

cc: The Honorable Max Baucus  
The Honorable Kent Conrad  
The Honorable Charles Grassley  
The Honorable Edward Kennedy  
The Honorable Michael Enzi  
The Honorable Harry Reid  
The Honorable Mitch McConnell