

October 2, 2012

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
The Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Essential Health Benefits

Dear Secretary Sebelius:

We, the undersigned, are health advocacy organizations representing millions of patients and their families who are committed to implementation of the Affordable Care Act (ACA). The manner in which the essential health benefits are defined will directly impact how well health coverage works or does not work for approximately 70 million patients. We are writing to urge you to ensure that the patient protections outlined in ACA will be meaningful, and the required prescription drug benefit will meet the treatment needs of all patients.

To date, the Department has issued no formal rules on essential health benefits but rather released a 13 page bulletin that outlines in broad terms the direction in which states should proceed in defining essential health benefits for the private market. Not included in that bulletin or in subsequent FAQs was any discussion of the patient protections mandated by law. According to ACA "the Secretary shall ensure that the scope of the essential health benefits ... is equal to the scope of benefits provided under a typical employer plan," but will also "not make coverage decisions . . . that discriminate against individuals because of their . . . disability" and will "take into account the health care needs of diverse segments of the population, including . . . persons with disabilities." As representatives of patient populations with complex and specialized health care needs, we look forward to the regulations that implement these patient protections and question how states can proceed with their plan design and have them approved without these protections in place.

One area in which the bulletin did detail how the mandated benefits should be defined, prescription medications, was done in such a manner that it would be completely unworkable for patients, particularly for those with serious chronic health conditions. Limiting medications to just one drug per class will not meet the needs of patients and certainly does not meet the non-discriminatory protections outlined in the law. We urge you to abandon this approach and instead require plans, for both the private insurance market and the expanded Medicaid population, to cover a full range of medications that will meet the needs of all patients.

A robust formulary is necessary because not all patients respond to medicines in the same way. Physicians may need to change medicines over the course of an illness, patients may need more than one medication from the same class at the same time, and patients taking multiple medicines need alternatives to avoid harmful interactions. Patients need access to a full range of medicines.

In the development of health plans, it is also imperative that patient cost-sharing be limited so that patients can afford access to lifesaving medications and other health care services. Additionally, it is critical that patients not be denied access to treatments through utilization management techniques such as step-therapy, prior authorizations, and quantity limits that impede quality care and treatment.

We thank you for your continued leadership in ensuring that more Americans will have access to health care. We realize that we are at a critical time in implementing ACA. Decisions that are made now will determine its success. On behalf of patients with many diverse chronic health conditions and disabilities, we look forward to the issuance of regulations that provide the patient protections outlined in ACA and a more meaningful prescription drug benefit.

Thank you very much.

Respectfully,

AIDS Action Committee of Massachusetts
AIDS Foundation of Chicago
The AIDS Institute
AIDS United
Alliance for Patient Access (AfPA)
Alzheimer's and Dementia Alliance of Wisconsin
American Autoimmune Related Diseases Association
American Brain Coalition
American Lung Association
Arthritis Foundation
Arthritis Foundation Mid Atlantic Region
California Hepatitis C Task Force
California Society of Addiction Medicine
Campaign for Better Health Care, Illinois
Coalition of Texans with Disabilities
Delaware HIV Consortium
Easter Seals
Epilepsy Foundation
Global Healthy Living Foundation
HealthHIV
Heartland Alliance for Human Needs and Human Rights
Hemophilia Association of the Capital Area
Huntington's Disease Society of America
Illinois Maternal and Child Health Coalition (IMCHC)
Indiana Association of Area Agencies on Aging
International Myeloma Foundation
Lupus Foundation of America
Maryland Society for Physical Medicine and Rehabilitation
Men's Health Network
Mental Health America

Mental Health America of Indiana
Michigan Association of Community Mental Health Boards
Nashville CARES
National Alliance of Mental Illness of Greater Chicago
National Alliance on Mental Illness (NAMI)
National Alliance on Mental Illness of Ohio
National Association of Hepatitis Task Forces
National Association of People with AIDS (NAPWA)
National Fibromyalgia & Chronic Pain Association
National Health Council
National Hemophilia Foundation
National Hemophilia Foundation (Delaware Valley Chapter)
National Hemophilia Foundation (Western PA Chapter)
National Kidney Foundation (Division Serving OH, KY and E. & Mid. TN.)
National Minority Quality Forum
National Multiple Sclerosis Society
National Psoriasis Foundation
Neuropathy Action Foundation
New England Hemophilia Association
Ohio Citizen Advocates
Parkinson's Action Network
Prevent Cancer Foundation
Society for Women's Health Research
Tennessee AIDS Advocacy Network
Treatment Communities of America
Veterans Health Council
Vietnam Veterans of America
Women Against Prostate Cancer
WomenHeart: The National Coalition for Women with Heart Disease