

Raise the Cap Coalition

May 7, 2010

Hon. Kathleen Sebelius
Secretary
The Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Sebelius:

On behalf of millions of patients with high-cost, chronic, and rare conditions and disorders, we are writing to urge you to implement the elimination of lifetime caps for all plans – new and grandfathered – on September 23, 2010. As you are aware, the Patient Protection and Affordable Care Act (PPACA) makes numerous important changes to the private insurance market, several of which are to take effect six months after enactment. While the elimination of lifetime caps is included among these "immediate" reforms, we are deeply concerned that insurers may be permitted to impose lifetime caps beyond the six month implementation date. We ask that you publicly request that insurers eliminate lifetime limits as of September 23, 2010, as they have agreed to do on rescissions and extension of dependent coverage.

The PPACA reforms the private insurance market to ensure that patients have access to life-saving treatments and prioritizes critical reforms to be implemented six months after enactment. In addition to eliminating lifetime limits in all plans, this new law also ends the practice of rescissions; eliminates pre-existing condition exclusions for children; and extends dependent coverage to age 26. While initial health reform proposals did not include grandfathered plans, we are very grateful that the final bill eliminated lifetime caps in both new and grandfathered plans and that all individuals will benefit from this critical reform.

While lifetime caps are intended to be prohibited six months after enactment, we continue to hear from insurers that lifetime caps are permissible until a new plan year begins, even though this may take place after September 23, 2010. This is contrary to how the other immediate reforms are being implemented. In recent weeks, you have led the charge in urging insurance companies to prohibit rescissions, eliminate pre-existing condition exclusions for children, and extend dependent coverage to age 26, even before the effective date in September.

We applaud your efforts and ask that you urge insurance companies to eliminate lifetime caps by September 23, 2010. President Obama and Congressional leaders have rightly championed the elimination of lifetime caps and have included it in the first round of private insurance market reforms to be implemented immediately. Individuals with high-cost, chronic and rare conditions must no longer be impeded in accessing necessary health care services or treatments, nor should they be impoverished by lifetime limits on benefits. We have the opportunity to provide the relief these individuals need and deserve, and appreciate your continued commitment to implementing and enforcing health care reform.

Sincerely,

Advocacy for Patients with Chronic Illness, Inc.
Alliance for Aging Research
Alpha-1 Advocacy Alliance
Alpha-1 Association
Alpha-1 Foundation
Alzheimer's Association
American Academy of Neurology
American Behcet's Disease Association
American Lung Association
American Society of Hematology
American Thoracic Society
Aplastic Anemia & MDS International Foundation
Autism Society
Batten Disease Support and Research Association
Baxter BioScience
Benign Essential Blepharospasm Research Foundation
Brain Injury Association of America
Breast Cancer Network of Strength
C3: Colorectal Cancer Coalition
Californians4Cures
CANN - Community Access National Network
Caring for Carcinoid Foundation
Children's Cause for Cancer Advocacy
Christopher and Dana Reeve Foundation
Cicatrical Alopecia Research Foundation
Colon Cancer Alliance
Committee of Ten Thousand
COPD Foundation
Costello Syndrome Family Network
Crohn's and Colitis Foundation of America
CSL Behring
Curesearch for Children's Cancer
Cystic Fibrosis Foundation
Cystinosis Research Network
Digestive Disease National Coalition
Dysautonomia Foundation
Dystonia Medical Research Foundation
Easter Seals
Ehlers Danlos National Foundation
Genetic Alliance
Hemophilia Federation of America
Hepatitis Foundation International
Hermansky-Pudlak Syndrome Network Inc.
Hope Street Kids
Huntington's Disease Society of America

Immune Deficiency Foundation
International Foundation for Functional Gastrointestinal Disorders
International Myeloma Foundation
Interstitial Cystitis Association
Kakkis EveryLife Foundation
Kids vs. Cancer
Lung Cancer Alliance
Mended Little Hearts
Mental Health America
National Alliance on Mental Illness
National Coalition for Cancer Survivorship
National Comprehensive Cancer Network
National Gaucher Foundation
National Hemophilia Foundation
National Kidney Foundation
National Lung Cancer Partnership
National Marfan Foundation
National MPS Society
National Organization of Rare Disorders
National Spinal Cord Injury Association
NephCure Foundation
Neurofibromatosis, Inc.
North American Brain Tumor Coalition
Ovarian Cancer National Alliance
Parent Project Muscular Dystrophy
Patient Services, Inc.
Phelan-McDermid Syndrome Foundation
Plasma Users Coalition
Project DCCC - Delivery of Chronic Care
Pulmonary Hypertension Association
PXE International
RetireSafe
Scleroderma Foundation
Sjögren's Syndrome Foundation
Suzanne Mintz National Family Caregivers Association
The AIDS Institute
The Ethical Factor
The Leukemia & Lymphoma Society
The Myositis Association
Tourette Syndrome Association
Trisomy 18 Foundation
United Mitochondrial Disease Foundation
United Spinal Association
Us TOO International Prostate Cancer Education & Support Network
VHL Family Alliance
WomenHeart: The National Coalition for Women with Heart Disease