

December 17, 2009

The Honorable Harry Reid
522 Hart Senate Office Bldg
Washington, DC 20510

The Honorable Christopher Dodd
448 Russell Senate Office Building
Washington, DC 20510

Dear Senators Reid and Dodd:

On behalf of the undersigned organizations and millions of Americans including those who suffer from chronic and rare diseases, such as inflammatory bowel disease, multiple sclerosis, hemophilia, lupus, primary immune deficiencies, and other debilitating illnesses, we thank you for your efforts to reform our health insurance system. We strongly support the insurance market reforms included in H.R. 3590, especially the elimination of lifetime limits on benefits. However, we are greatly concerned about an issue implicated by the Senate health insurance reform bill, annual limits on benefits.

In recent years, medical advances have done much to improve the lives and health of patients with immune and autoimmune diseases and bleeding disorders. However, these new medical treatments and strategies come at a cost. Depending on where patients receive intravenous medication, the cost of this care may well exceed \$100,000 per year.

We strongly support Amendment No. 3218 offered by Senator Dorgan, which would phase out lifetime caps on benefits under existing (grandfathered) health plans. A similar change is needed for Section 2711 and 1251 of H.R. 3590, which would allow insurers to initiate and/or maintain annual limits on benefits. We are aware of plans today – typically individual plans – that limit annual benefits to \$50,000 or \$100,000. A widespread adoption of limits like these in both the group and individual markets would adversely affect access to health care by many Americans. Insurers who are forced to eliminate pre-existing condition exclusions and lifetime caps will, we fear, initiate annual caps as a way to control their costs despite the fact that an individual mandate will bring them many thousands of young, healthy insured individuals. We ask you please make sure this does not occur.

Annual caps are at least as harmful as lifetime caps. A patient who reaches a lifetime cap under a group insurance plan at least has the option of enrolling in a guaranteed issue plan under HIPAA. However, a patient who reaches an annual cap has nowhere to go – no HIPAA plan, no COBRA, no recourse, and no access to health care.

In addition, in context, the amount of money this would save insurers is relatively small when spread over the entire population. Whereas there are thousands of patients who need these expensive medications, the numbers are relatively small when spread over the entire population of insured individuals. What would have disastrous consequences for patients would not be critical to insurers' bottom line.

Although we are acutely aware of the multitude of issues that you must resolve in finalizing health insurance reform, we hope that you will fully appreciate the importance of this issue to the millions of people who suffer from chronic and rare diseases. We ask that you ensure, in addition to the elimination of lifetime caps pursuant to Senator Dorgan's amendment, annual caps are also eliminated from the final version of the Senate Bill. Thus,

we respectfully request that you amend H.R. 3590 to eliminate annual limits effective in 2010.

Respectfully,

Advocacy for Patients with Chronic Illness, Inc.
Alliance for Aging Research
Alpha-1 Association
Alpha-1 Foundation
American Autoimmune Related Diseases
Association
Aplastic Anemia &MDS International Foundation
Baxter BioScience
BioMarin Pharmaceuticals
Brain Injury Association of America
Breast Cancer Network of Strength
Colon Cancer Alliance
Committee of Ten Thousand
Community Health Charities of America
Cooley's Anemia Foundation
COPD Foundation
Crohn's & Colitis Foundation of America
CSL Behring
Digestive Disease National Coalition
Dystonia Medical Research Foundation
Gaucher Conference Committee
GBS/CIDP Foundation International
Grifols, Inc.
Hemophilia Federation of America
Hepatitis Foundation International
Huntington's Disease Society of America
Immune Deficiency Foundation
International Foundation for Functional
Gastrointestinal Disorders
Interstitial Cystitis Association
Jeffrey Modell Foundation
Lybba
Mended Little Hearts
National Hemophilia Foundation
National Marfan Foundation
National PKU Alliance
National Multiple Sclerosis Society
National Spinal Cord Injury Association
Patient Services, Inc.
Plasma Users Coalition
Pulmonary Hypertension Association
Ryan Foundation for MPS Children
Scleroderma Foundation
United Spinal Association