



October 7, 2011

The Honorable Patty Murray
Co-Chairman
Joint Select Comm. on Deficit Reduction
United States Senate
Washington, DC 20510

The Honorable Jeb Hensarling
Co-Chairman
Joint Select Comm. on Deficit Reduction
United States House of Representatives
Washington, DC 20515

Dear Co-Chairs Murray and Hensarling:

The American Plasma Users Coalition (A-PLUS) is a coalition of national patient advocacy organizations created to address the unique needs of over 125,000 patients with rare diseases that use life-saving plasma protein therapies. The coalition represents disorders such as Alpha-1 antitrypsin disorder, Guillain-Barre syndrome/chronic inflammatory demyelinating polyneuropathy, hemophilia, primary immunodeficiency diseases (PIDD) and platelet disorders. These patients need life-long access to expensive, life-saving treatments, and it is only with continued access to these needed treatments and specialized medical professionals, that our patients lead productive lives.

A-PLUS recognizes the challenges facing the Joint Select Committee on Deficit Reduction (“Committee”) in reducing health care spending. We respectfully request that you consider the impact that various proposals could have on individuals with high-cost, rare, chronic conditions. In particular, we respectfully request that you not include the following potential proposals in your Committee’s recommendations to Congress, since they would severely impact the patients we represent:

Reclassification of treatments currently covered in Medicare Part B into Part D: We oppose transferring plasma-based therapies from Part B to Part D, since this would result in a significant cost shifts to patients. Given their extremely high costs, our therapies would likely be designated as tier 4 specialty drugs. With a co-insurance level of 30%, patients could be required to pay significant out-of-pocket costs in the tens to hundreds of thousands of dollars. Since very few people could afford those costs, it is likely that patients will under-medicate or go without treatment. Forgoing needed treatment can result in severe and life-threatening consequences for patients, and moreover, treating these complications will only increase future health care costs.

Reduction of Medicare Part B reimbursement from Average Sales Price (“ASP”) +6%: Decreasing reimbursement below the current ASP +6% rate for Part B therapies will harm patient access to needed therapies. When reimbursement was reduced for immunoglobulin replacement therapy (IVIG) in the mid-2000s, patients faced significant challenges in finding a site of care that would treat them, resulting in many adverse health impacts. This was reported to Congress by the Office of Inspector General in 2007 as well as a similar report in the same year from the Assistant Secretary of Program Evaluation (ASPE).

Medigap insurance policies: We do not support proposals to limit first-dollar coverage in Medigap insurance policies. Many of our patients rely on Medigap plans to reduce their out-of-pocket spending. Such limitations will again adversely impact access to patient care by forcing additional costs onto patients who most likely will not be able to afford treatment.



We respectfully request that you protect Medicare beneficiary access to the life-long therapies necessary to maintain good health. Without treatment our patients will sustain serious, severe and life threatening adverse health events. We believe that making health care unaffordable for patients with rare and chronic diseases to live healthy lives is more costly to the overall health care system.

Thank you for your consideration. Please contact Larry LaMotte with the Immune Deficiency Foundation, at llamotte@immunedeficiency.org, if you need any more information.

Sincerely,

Alpha-1 Association
Alpha-1 Foundation
GBS/CIDP Foundation International
Committee of Ten Thousand
Hemophilia Federation of America
Immune Deficiency Foundation
Jeffrey Modell Foundation
National Hemophilia Foundation
Platelet Disorder Support Association
Patient Services Incorporated