July 15, 2011

The Honorable John Boehner
Speaker of the U.S. House of Representatives
1011 Longworth House Office Building
Washington, DC 20515

The Honorable Harry Reid
Majority Leader of the United States Senate
522 Hart Senate Office Building
Washington, DC 20510

The Honorable Eric Cantor
Majority Leader of the U.S. House of Representatives
303 Cannon House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader of the United States Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Nancy Pelosi
Minority Leader of the U.S. House of Representatives
235 Cannon House Office Building
Washington, DC 20515

Dear Speaker Boehner, Leader Reid, Leader Cantor, Leader McConnell and Leader Pelosi:

The American Plasma Users Coalition (A-PLUS) seeks your support to protect Medicare beneficiary access to the therapies they rely on to maintain health. We recognize the need to address the federal budget and believe this can be accomplished without threatening patient access to health care. A-PLUS is a coalition of national patient organizations created to address the unique needs of over 125,000 patients with rare diseases that use life-saving plasma protein therapies. Our patients, who are dependent on blood plasma therapies to lead healthy, active and productive lives, believe that reductions in Medicare reimbursement for critical therapies or shifting more costs to Medicare beneficiaries, such as, increases in premiums, co-insurance or co-payments, would seriously and immediately jeopardize the physical and economic health, of our patients and their immediate and extended families. Our patients rely on regular infusions of Part B drugs which must be taken for long durations, usually a lifetime, to maintain health and prevent severe health consequences.

We understand that one of the proposals that has been raised during the debt ceiling negotiations is to reclassify Part B drugs to Part D. A transfer of blood-product-based therapies to Part D would be catastrophic for our communities. There is no other word for it. Because our patients need blood plasma therapies to be healthy and productive, a reclassification to Part D will result in significant cost shifts to families that will force Medicare beneficiaries to under-medicate at best or go without treatment at worst with severe and life threatening consequences.

Medicare Part B covers drugs that are furnished “incident to a physician’s service,” administered using durable medical equipment (DME), and specifically covered by statute.

Part B drugs that are shifted to Part D will most likely end up as a specialty tier drug because of the high cost of the drugs. In doing so, the co-insurance required to be paid by Medicare beneficiaries will skyrocket to the point where a beneficiary has to choose between economic bankruptcy or life-saving treatment. At a 30% co-insurance level our patients may need to pay out of their pocket anywhere between $30,000 to several hundreds of thousands of dollars. How many Americans can afford that?
The consequence of no treatment is extensive and on-going use of the overall health care system, disability and death. This proposal coupled with other proposals being discussed, such as prohibiting Medigap policies from offering first dollar coverage, saddle our patient communities with unmanageable out of pocket costs for therapies that are life-sustaining, not optional.

In addition, we are concerned about any plans to lower the Average Sales Price (ASP) reimbursement formula. Patients requiring intravenous immunoglobulin replacement therapy (IVIG), a plasma therapy, were so severely impacted in the mid 2000s, that those patients had difficulty 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.

Congress has numerous times in past Medicare legislative negotiations recognized the challenges our patients face -- the combination of high-cost medications and a chronic condition needing a lifetime of care -- and protected their access to care. We ask that you continue to protect these vulnerable Americans.

We urge you to not reclassify Part B drugs to Part D, as well as maintain current reimbursement of Part B drugs.

Alpha-1 Association  
Alpha-1 Foundation  
Committee of Ten Thousand  
Hemophilia Federation of America  
Immune Deficiency Foundation  
Jeffrey Modell Foundation  
National Hemophilia Foundation  
Patient Services Incorporated