



Chairman Ryan  
Committee on Ways and Means  
1102 Longworth HOB  
Washington, D.C. 20515

Chairman Upton  
Committee on Energy and Commerce  
2125 Rayburn HOB  
Washington, D.C. 20515

Chairman Kline  
Committee on Education and the Workforce  
2181 Rayburn HOB  
Washington, D.C. 20515

RE: Out-of-pocket cost-sharing limits

September 21, 2015

Dear Chairman Ryan, Chairman Upton, and Chairman Kline:

The American Plasma Users Coalition (A-PLUS) is a coalition of national patient organizations created to address the unique needs of patients with rare diseases that use life-saving plasma protein therapies. The organizations representing these patients share a common desire to ensure that the patient voice is heard when relevant public policies, regulations, directives, guidelines, and recommendations which have a major impact on their access to safe and effective therapy and treatment are considered. Together, our coalition represents more than 125,000 Americans living with chronic disorders dependent upon plasma protein therapies for their daily living.

These necessary therapies can be very expensive, which is why we were encouraged by a recent decision by the Department of Health and Human Services (HHS) to apply the Affordable Care Act's (ACA) individual out-of-pocket limit to any individual, whether that person is enrolled in a self-only or a family plan.

While the ACA has led to an increase in coverage, there can be high out-of-pocket (OOP) cost-sharing in ACA plans. Due to the cost of plasma protein therapies, our patients usually will meet any deductible each and every year, and, depending on the progression of their illness, even meet the OOP limits as well. To double the OOP cap simply because a patient is enrolled in a family plan makes little sense because it assumes two incomes where there may be only one. For example, a single parent who purchases coverage for himself and his dependent child should not be penalized for



doing so. Chronically ill patients who need expensive, specialty medications should not be penalized for their family structure and its effect on the type of insurance policy they purchase.

We respect the procedural questions you have noted with HHS' proposal and do not wish to diminish those in any way. Rather, we ask you to consider the real-world impact of this policy and the patients who benefit from it. HHS' decision to apply the individual OOP cost-sharing limit to any person, whether covered via a self-only or family plan, is a tremendous help to patients who incur staggering medical costs. On behalf of the patients we represent, we urge you to allow this OOP change to proceed. Please do not hesitate to contact one of the undersigned organizations, should you have any questions or require additional information.

Sincerely,

Alpha-1 Foundation  
GBS/CIDP Foundation International  
Committee of Ten Thousand  
Hemophilia Federation of America  
Immune Deficiency Foundation  
Jeffrey Modell Foundation  
National Hemophilia Foundation  
National Organization for Rare Disorders (NORD)  
Patient Services Incorporated  
Platelet Disorder Support Association  
US Hereditary Angioedema Association