



May 13, 2014

Marilyn Tavenner
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Patient Protection and Affordable Care Act; Third Party Payment of Qualified Health Plan Premiums;
CMS-9943-IFC

Dear Administrator Tavenner:

The American Plasma Users Coalition (APLUS) 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. Together our coalition represents more than 125,000 Americans living with chronic disorders who depend upon plasma protein therapies to lead healthy, productive lives. We are writing to express concerns that the proposals included in the interim final rule on third-party payment of qualified health plan (QHP) premiums will preclude patient assistance programs from assisting individuals in QHPs, jeopardizing our patients' abilities to access the treatments they need.

While the Affordable Care Act (ACA) includes many important protections that benefit our patients, enrollees in QHPs with complex, chronic conditions often need access to a broad array of patient assistance programs that can help them to afford their insurance premiums and cost-sharing. While the institution of the out-of-pocket max allows a family to predict what their health care expenses will be in a year, our patients are likely to hit their out-of-pocket max every year since their treatments can cost hundreds of thousands of dollars per year or more. Depending on their insurance plan's benefit design, people could be forced to pay the entire \$6,350 or \$12,700 out-of-pocket max in the first month or two of the year. Most families cannot afford this cost and need access to patient assistance programs to ensure they can access these life-saving therapies and remain adherent to their treatment regimens.

As one example, one of our coalition members is Patient Services Incorporated (PSI), a national non-profit patient assistance organization that provides health insurance premium assistance as well as copayment assistance for individuals treated with plasma-based products. PSI originated the copayment foundation model for patient assistance in the United States, which is now used by at least 8 other organizations to assist hundreds of thousands of patients in obtaining the treatments they need to live and to maintain their quality of life. Our patients benefit from other non-profit patient assistance programs, such as those created by our patient advocacy group members, as well.



We are concerned that the interim final rule's provisions will preclude non-profit patient assistance programs from assisting people in QHPs. Although the interim rule provides explicit clarification of the acceptability of premium and cost-sharing payments made on behalf of enrollees by the Ryan White HIV/AIDS Program and other Federal and State government programs, it is silent on whether non-profit patient assistance programs can serve individuals in QHPs. This lack of clarity has already had dire consequences for patients in Louisiana who are being denied the ability to utilize financial assistance from non-profit third party payers. This policy directly contradicts the treatment of financial assistance in Medicare, and is exacerbating affordability challenges for enrollees with expensive and chronic conditions, especially in states that have not taken advantage of the Medicaid expansion option.

The financial services that these programs provide for patients with few treatment alternatives neither skew insurance risk pools nor increase the number of patients seeking care. Rather, these lifeline services may be the only way that a patient can access treatment, without which they could face potentially catastrophic consequences and ultimately may tax the healthcare system more as emergency care and increased hospitalizations are required. APLUS requests that HHS clarify and make explicit that QHPs must accept payments from third-party non-profit patient assistance programs.

Thank you for the opportunity to submit comments. If you have any questions, your staff can reach James Romano at jromano@uneeedpsi.org or Larry La Motte at llamotte@primaryimmune.org. We look forward to this issue being addressed in a timely manner so that no more QHP enrollees are denied access to this vital assistance.

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
Patient Services Incorporated
Platelet Disorder Support Association
US Hereditary Angioedema Association