

September 22, 2009

Honorable John Kerry  
United States Senate  
Washington, DC 20510

RE: Support for Kerry Amendment C-5, Medicare patient access to IVIG treatment

Dear Senator Kerry:

Thank you for filing your intent to offer amendment C-5 which addresses Medicare patient access to intravenous immune globulin (IVIG). We appreciate your continued leadership on this issue and write to support your amendment and urge its passage.

As patients and the physicians and nurses who treat patients that require IVIG therapy, we know that Medicare beneficiary access to IVIG is vital in treating patients with frequent life-threatening infections and debilitating illnesses. These include patients with primary immunodeficiency diseases, autoimmune and neurological conditions such as: chronic inflammatory demyelinating polyneuropathy, Guillain-Barré syndrome, idiopathic thrombocytopenic purpura, myasthenia gravis, myositis, multiple sclerosis, pemphigus; as well as certain types of cancer and other chronic illnesses. Without access to IVIG therapy, these patients experience a poor quality of life, disability and potentially death.

Government-sponsored studies have demonstrated the difficulty Medicare patients routinely experience trying to locate providers willing to provide IVIG infusions. In April 2007, the U.S. Department of Health and Human Services (HHS) Office of the Inspector General (OIG) reported that Medicare reimbursement for IVIG does not cover the cost many providers must pay for the product. In fact, the OIG found that 44 percent of hospitals and 41 percent of physicians were unable to purchase IVIG at the Medicare reimbursement rate during the 3<sup>rd</sup> quarter of 2006. The previous quarter had been even worse: 77.2% of hospitals and 96.5% of physicians were unable to purchase IVIG at the Medicare reimbursement rate. This situation continues to occur today and with the Kerry amendment's review of different reimbursement formulas and the lag period we hope to find solutions to allow all providers to treat all patients in all sites of care.

An astounding 61 percent of responding physicians indicated they had no choice but to send patients to hospitals for IVIG treatment, instead of providing this therapy in a physician's office, due to their inability to purchase IVIG at prices below Medicare reimbursement. Some physicians reported that they stopped providing IVIG altogether to patients with Medicare. Indeed, the current situation seriously jeopardizes patient care for individuals with compromised health.

Like S. 701, the ***Medicare Patient IVIG Access Act of 2009***, your amendment assists all Medicare beneficiaries in need of IVIG therapy by requiring the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services to collect and review data related to the cost of furnishing IVIG compared to Medicare reimbursement for IVIG. In addition, your amendment asks ASPE to review payment of IVIG and make recommendations to Congress to improve access to IVIG for

Medicare beneficiaries and calls upon ASPE to review and report back to Congress regarding which of the current complexity codes for of the administration of IVIG is most appropriate.

We support access to home infusion for all Medicare beneficiaries requiring IVIG. Last Congress, ASPE reported, *“home infusion services generally do not accept new primary immune deficiency patients with only Medicare coverage...because healthcare providers are not reimbursed for the infusion service.”* The current Part B benefit does not provide coverage for items and services related to the administration of IVIG in the home. Your amendment will close that gap and make the Part B benefit whole.

Your leadership on this issue will impact the lives of thousands of patients for whom IVIG is a lifeline, allowing them to remain healthy and productive members of their communities.

Sincerely,

Immune Deficiency Foundation  
Alliance for Plasma Therapies  
American Academy of Asthma, Allergy and Immunology  
American Partnership for Eosinophilic Disorders  
A-T Children’s Project  
Clinical Immunology Society  
Foundation for Peripheral Neuropathy  
GBS/CIDP Foundation International  
Infusion Nurses Society  
International Pemphigus and Pemphigoid Foundation  
Jeffrey Modell Foundation  
The Myositis Association  
National Patient Advocate Foundation  
The Neuropathy Association  
Neuropathy Action Foundation  
Patient Services Inc.  
Platelet Disorder Support Association