Immune Deficiency Foundation Applauds Legislation to Improve Patient and Provider Access to Immunoglobulin Products

(WASHINGTON, D.C., JULY 28, 2007) – The Immune Deficiency Foundation (IDF) applauds Congressman Kevin Brady (R, TX) who introduced (H.R. 2914), known as the Medicare IVIG Access Act of 2007. With bipartisan support, the bill seeks adequate reimbursement for Intravenous Immunoglobulin (IVIG) products and accompanying care in the management of patients with primary immunodeficiency diseases (PIDD) and other serious conditions that require IVIG therapy.

“For most patients living with primary immunodeficiency diseases, IVIG is their only treatment option,” said Marcia Boyle, IDF President and Founder. “The delay or denial of treatment which is occurring under current Medicare reimbursement standards is putting patients at tremendous risk for serious, life threatening complications.”

Because of medical advances like IVIG, many individuals affected by primary immunodeficiency diseases can live normal lives. Without treatment, everyday illnesses like the common cold can put them at risk for infection and more serious complications. Negative health consequences reported by these patients include more infections generally, pneumonia, bronchitis, and increased use of antibiotics.

The current IVIG access and care issue began in January 2005 as a result of the Medicare Modernization Act under Part B, which changed the way physicians and hospital outpatient departments were paid under Medicare. The law reduced IVIG reimbursement rates such that most physicians in outpatient settings could no longer afford to treat Medicare patients requiring IVIG, and either delaying regular treatment or sending many patients to a hospital clinical setting.
for therapy. Patient access was further complicated in 2006 when similar payment changes went into effect for hospital outpatient departments.

Specifically, the bill seeks to improve health outcomes and quality of life for PIDD patients by:

- Improving reimbursement for IVIG products as well as ancillary services
- Allowing for home infusion provisions to cover administrative services
- Maintaining pre-administration fees that allow providers to obtain IVIG products

A comprehensive patient survey conducted by IDF that supports today’s announcement found that Medicare patients, when compared to their private pay insurance counterparts, share a disproportionate burden of negative consequences as a result of the changes in Medicare IVIG reimbursement policies. Since January 2005, more than 40 percent of Medicare PIDD patients reported that their treatments had been postponed, with 26 percent reporting serious health consequences as a result of these delays. Additionally, 32 percent of the Medicare patients reported they have been forced to change their preferred IVIG treatment location. Many of these patients now must receive their IVIG in hospitals, which is not the ideal location for patients who are immunodeficient.

An IDF physician survey also found that 51 percent of physicians treating PIDD patients said they have had patients change their site of IVIG therapy because of Medicare reimbursement, and nearly half said they believe that current Medicare IVIG reimbursement policies pose a serious risk to the health of their patients.

“Through my work with IDF and the patients and their families living with PIDD, this issue has become very close to me personally,” adds Rep. Brady. “This bill, along with the strong endorsements of my colleagues on the Hill, shows that we have heard their voices in Washington, and they are not alone.”

Multiple patient, professional and manufacturer organizations contributed to today’s announcement, including IDF, the Clinical Immunology Society, Jeffrey Modell Foundation, GBS/CIDP Foundation International, the Plasma Protein Therapeutics Association, Platelet Disorder Support Association, ASD Healthcare and Accredo Health.
About Primary Immune Deficiency Diseases

Primary immunodeficiency diseases are disorders in which part of the body's immune system is missing or does not function properly. In contrast to secondary immune deficiency disease in which the immune system is compromised by factors outside the immune system, such as viruses or chemotherapy, the primary immunodeficiency diseases are caused by intrinsic or genetic defects in the immune system.

Approximately 250,000 people in the United States are diagnosed with primary immune deficiency diseases. There are over 130 different primary immunodeficiency diseases, including X-linked Agammaglobulinemia (Bruton's Disease), Common Variable Immune Deficiency, Selective IgA Deficiency, and Severe Combined Immune Deficiency (boy-in-the-bubble disease). Some disorders, such as Selective IgA Deficiency can be quite common, occurring as often as 1/500 to 1/1000 individuals. Others, such as Severe Combined Immune Deficiency, may be as rare as one individual affected per million. Untreated primary immunodeficiencies may be characterized by frequent life-threatening infections and debilitating illnesses.

Because of advances in our medical understanding and treatment of primary immunodeficiency diseases, individuals who in the past would not have survived childhood are now able to live normal lives. Many individuals affected by primary immunodeficiency diseases require life long therapies including intravenous gamma globulin infusions, antibiotic therapies, or bone marrow transplantation. The Immune Deficiency Foundation is dedicated to improving the diagnosis and treatment of primary immunodeficiency diseases through research, education and advocacy.

About The Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF), founded in 1980, is the national non-profit patient organization dedicated to improving the diagnosis and treatment of patients with primary immunodeficiency diseases through research, education, and advocacy.

People with primary immunodeficiency diseases often find it difficult to receive specialized health care, and proper diagnosis and treatment. Individuals affected by primary immunodeficiency diseases also experience difficulties financing their health care, finding educational materials on the disease, and locating others with whom to share their experiences. The goal of IDF is to help individuals overcome these difficulties and live healthy and productive lives. To learn more about IDF visit www.primaryimmune.org

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