

**For Immediate Release**

## **New Bill Offers Medicare Reimbursement Fix for Intravenous Immune Globulin**

**18 patient advocacy and health care professional groups join with Congressional sponsors Reps. Israel, Brady and Schwartz to announce new legislation; call for patient access to IVIG**

**WASHINGTON, D.C. April 22, 2009** – Members of Congress and patient advocacy groups announced today the introduction of new legislation – H.R. 2002, Medicare Patient IVIG Access Act of 2009 – meant to remedy inadequate Medicare reimbursements that currently restrict patient access to Intravenous Immune Globulin (IVIG), a life-saving and life-enhancing therapy for many primary immunodeficiency diseases; chronic lymphocytic leukemia; Kawasaki disease; autoimmune and neurological conditions such as chronic inflammatory demyelinating polyneuropathy, Guillain-Barre syndrome, idiopathic thrombocytopenic purpura, myasthenia gravis, myositis, multiple sclerosis, just to name a few.

Sponsored by Reps. Israel, Brady and Schwartz, this bill is similar to legislation introduced by Sens. Kerry and Alexander in March of this year. Passage of this legislation would benefit Americans nationwide for whom IVIG is a necessary therapy to help them live with their primary immunodeficiency disease, neurological, autoimmune or other rare chronic conditions and illnesses.

“For those suffering with immune-deficiency disorders, IVIG is a life-saving and life-sustaining treatment. But because of inadequate Medicare coverage, patients are suffering,” said Rep. Steve Israel. “We must fix the insufficient coverage Medicare provides for IVIG treatment, which is why I’m sponsoring legislation to help get these patients the care they need.”

“Access for those who rely on IVIG therapy to sustain a normal life is an issue that must be addressed, and we are doing so by introducing this bill,” said Rep. Kevin Brady. “Through my work with patients and families living with conditions that rely on IVIG, the access issue has become very close to me personally and a cookie-cutter approach like Medicare can be dangerous to this unique treatment.”

Eighteen patient advocacy groups and health care professional organizations, including the Immune Deficiency Foundation and the Alliance for Plasma Therapies, already have endorsed the bill via a joint letter of support, and IVIG patients and caretakers echoed that support while sharing their personal struggles in trying to access IVIG therapy during a briefing for stakeholders today. Special guests and patient advocates included Terri Cerda, who, together with her two young daughters, battles combined immunodeficiency disease and whose family will be featured on the May 10 episode of ABC’s “Extreme Makeover: Home Edition,” and Nebraska State Senator Abbie Cornett, who has common variable immunodeficiency disease. Other speakers included Jenny Gardner, a patient with common variable immunodeficiency; Lt. Col. Eugene B. Richardson, ret., who has progressive chronic polyneuropathy; and Craig Orfield, staff of Senator Enzi who has idiopathic thrombocytopenic purpura.

“Since 2005, patient access to IVIG has diminished, and Medicare beneficiaries throughout the country have experienced major health problems because of reimbursement reductions,” said Marcia Boyle, founder and president of the Immune Deficiency Foundation. “We are grateful for the support of Representatives Israel, Brady and Schwartz and their sponsorship of this critical legislation that is designed to restore access to this vital therapy, and we are heartened by the overwhelming support from the patient advocacy community.”

“Today is an unprecedented day to see so many different disease groups come together as a unified voice to strongly urge Congress to fix the unintended consequence of the Medicare Modernization Act which has caused Medicare beneficiaries to lose access to their lifesaving plasma therapy, IVIG, and has caused detrimental consequences to their health,” said Michelle Vogel, executive director of the Alliance for Plasma Therapies. “We applaud Representatives Israel, Brady and Schwartz for championing this issue to restore patient access to this vital therapy in all sites of care.”

**About the Immune Deficiency Foundation**

The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education, and research. To learn more about IDF, visit [www.primaryimmune.org](http://www.primaryimmune.org)

**About the Alliance for Plasma Therapies**

The Alliance for Plasma Therapies is a national non-profit organization established to provide a unified, powerful voice of patient organizations, healthcare providers and industry leaders to educate about the diseases that rely on plasma derived therapies and advocate for fair access to plasma therapies for patients who benefit from their lifesaving effects. To learn more about the Alliance, visit [www.plasmaalliance.org](http://www.plasmaalliance.org).

**Patient Advocacy Organizations and Professional Societies Supporting the Medicare Patient IVIG Access Act of 2009**

Immune Deficiency Foundation, Alliance for Plasma Therapies, American Academy of Asthma, Allergy and Immunology, American Autoimmune Related Diseases Association, 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., and Platelet Disorder Support Association.

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