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NEUROPATHY PATIENTS, DOCTORS AND MEDICAL PROFESSIONALS RALLY IN SACRAMENTO TO DEMAND ACCESS TO LIFESAVING MEDICAL TREATMENTS

California Assemblymember Mary Hayashi Calls on California Congressional Delegation to Remember Needs of Neuropathy Patients at 3rd Annual "Neuropathy Action Awareness Day"

SACRAMENTO (June 25, 2009) - As President Obama continues his push for national health care reform, more than 300 neuropathy patients, physicians and medical professionals gathered in Sacramento today to call on Congress to restore access to life-sustaining and lifesaving treatments for neuropathy patients. At a press conference kicking off the third annual "Neuropathy Action Awareness Day," California Assemblymember Mary Hayashi and those in attendance signed a petition encouraging the California Members of Congress to remember the needs of neuropathy patients while working on federal health care reform legislation.

"Neuropathy patients and advocates in California spoke with one voice today to demand access to the lifesaving treatments we need, and to help ensure that Congress protects neuropathy patients as it continues the national health care reform debate," said Michelle Vogel, Executive Director of the Alliance for Plasma Therapies. "As President Obama and Congress look for ways to cut health care spending, they must also restore access to critical therapies such as IVIG (intravenous immune globulin) which is used to treat patients suffering from neuropathy, multiple sclerosis, myositis and pemphigus among other conditions."

Neuropathy Action Awareness Day, sponsored by the Neuropathy Action Foundation (NAF) and the Alliance for Plasma Therapies (APT), gathered patients, physicians and medical professionals to learn about neuropathy and to promote awareness of the disease. Patients and patient advocates in attendance signed a petition, to be delivered to the California Congressional delegation, which stated:

We, the undersigned, respectfully ask the Members of Congress from the State of California to co-sponsor H.R. 2002 and S. 701, the Medicare Patient IVIG Access Act of 2009, which restores access in all sites of care to intravenous immune globulin (IVIG) to patients who rely on this lifesaving therapy. We further ask our Members of Congress to remember, while debating healthcare reform, that all patients, especially those with rare diseases, need access to all therapies prescribed appropriately by their physician and that because every patient is unique, personalized medicine must play a role in diagnosing and treating patients with all diseases.

"Every time my neurologist orders a treatment, managed care denies the request, and each time I have to file an appeal to receive the treatment that my doctor thinks is best," said Stacey Westurlund, a 31-year old social worker and neuropathy patient from Lodi, CA, who spoke at the press conference today. "I have to employ my skills as a social worker to become my own advocate - researching available treatment options, partnering with my doctors, and appealing managed care and insurance company decisions."

Westurlund, who signed the petition to Members of Congress after Assemblymember Hayashi, was misdiagnosed for a year before being diagnosed with a form of polyneuropathy. Stacey benefits from regular treatments of IVIG at home through Medicare, but because her painful condition keeps her from driving, she was forced to fight health insurers for months until she got coverage to receive her treatments at her home.

"The last major health care reform legislation passed by Congress decreased Medicare reimbursements for neuropathy patients and increased obstacles to getting timely and effective treatment," said Michelle Vogel. "In addition to restoring access to treatment for all Americans, Congress should enable physicians, not health insurers, to determine what is best for patients and what constitutes medically necessary care."

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