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## **Neuropathy Task Force Sends Recommendations to Legislature**

SACRAMENTO, Calif. – The Legislative Task Force on Peripheral Neuropathy has released a series of recommendations to the California State Legislature regarding public and physician awareness of peripheral neuropathy, as well as promoting early diagnosis, treatment and management of the disease.

Some of the recommendations would require legislative or executive branch action, while others would require coordination of stakeholders and private funders. As health care costs increase at a pace that is three times inflation, Assemblywoman Mary Hayashi (D-Hayward) co-chaired the meeting in recognition of the approximate 2 million Californians who live with the disease, characterized by numbness, pain and weakness. In spite of its prevalence, many people – including physicians -- have never heard of it.

"People who suffer from neuropathy should be heard, diagnosed and treated properly," said Assemblywoman Hayashi, who serves on the Assembly Health Committee. "Having the persistent pain from neuropathy is debilitating enough without having to convince your doctor that you are actually in pain." James Lee, Neuropathy Action Foundation Board member, said the lack of Neuropathy awareness is "beyond frustrating for patients."

The task force, comprised of providers specializing in neuropathy, researchers of the disease, patient advocates and pharmaceutical companies, heard presentations about Neuropathy and new research that could help better understand the roots of the disease and the discussion on three issues; public and physician awareness, access to proper treatment and early diagnosis and treatment.

Recommendations for increasing public and physician awareness include the following:

- Creating a statewide public affairs campaign around Neuropathy, including a Neuropathy Day at the State Capitol and identifying legislators and their staff affected by Neuropathy;
- Holding community forums for providers, as well as regional presentations on neuropathy to educate primary care providers and others about the disease;
- Conducting outreach to medical schools and residency programs to encourage neuropathy education as part of the curriculum or as part of a residency or intern program.

In order to increase access to appropriate treatment, task force recommendations include the following:

- Introduce and support legislation that would prohibit step therapy, fail first and forced off-label policies;
- Promote the premise that patients should have access to their prescribed therapies and medications based on clinical need without influence by payers:
- Create a neuropathy coalition that develops a "best practices" model through the Department of Public Health, using the Diabetes Coalition's efforts as a template.

Lastly, the task force has recommended frequent statewide mandatory awareness screenings, mandate a curriculum that includes physical activity for elementary, middle and high schools, and create regional centers of excellence focused on Neuropathy in order to promote understanding of early diagnosis, treatment and management.



Neuropathy has often been difficult to diagnose, leading to years of pain and increased health care costs for patients who feel unheard. Individuals who have been diagnosed are running into roadblocks from their health care plans or insurers. These health care plans or insurers are not covering costs associated with purchasing and administering proper treatment and often times practice step therapy policies in an attempt to control costs. Some plans require neuropathy patients to try up to five different medications before they are granted access to the treatment prescribed by their physician. Health care plans also force neuropathy patients to take medications that are not FDA-approved for treating their disease, also known as off-label medications. Patients are being forced to try less expensive drugs before they are approved for the medication deemed best fit by their physician. Such policies take health care decisions out of the hands of physicians and have the potential to cause a great deal of harm to patients.

For more information on the Task Force Recommendations contact Neuropathy Action Foundation at (877) 512-7262.

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