

New Office Supports Patient Advocacy

By Kathy Stone

While the National Multiple Sclerosis Society (NMSS) was working on a multi-year advocacy effort that culminated in Congress's passage of the Medicare Rx Drug Discount Act of 2003, the American Academy of Neurology (AAN) was by its side.

Susan Sanabria, vice president of advocacy programs for the NMSS says the AAN worked alongside her organization to gain congressional approval for a nationwide Medicare demonstration project that enabled eligible MS patients to receive four injectable prescription therapies at reduced costs before the formal launch of the drug benefit program in January 2006. And, this fall, the AAN is working with the NMSS and six other patient advocacy organizations to educate physicians and patients about the new prescription drug program as they sort through the plan's enrollment options.

Power in Numbers

The AAN, which is headquartered in St. Paul, Minn., opened its Washington, D.C., office this past June to lobby Capitol Hill more effectively on behalf of neurologists and patients.

Mike Amery, who represents the AAN as its legislative counsel in the new office, says the AAN partners on lobbying efforts with about 15 patient advocacy groups. The

Academy sends out alerts to its members and works on important legislation affecting patients with neurological diseases, hosts lobbying days when neurologists from all over the country convene at the Capitol to meet with congressional leaders and presents expert testimony at congressional hearings.



AAN members meet with Sen. Norm Coleman during the AAN's annual Neurology on the Hill event last May. Pictured left to right are Linda Marden, M.D., Brainerd Medical Center; Mike Amery; Sen. Coleman; Robert Van Boven, M.D., D.D.S., Northern Neurology Center; and John Gates, M.D., Minnesota Epilepsy Group.

When groups band together, they can make a major impact on national policies, he notes. The AAN was successful, along with other medical and advocacy groups, in doubling the research funding for the National Institutes of Health, including the National Institute for Neurological Disorders and Stroke in Fiscal Years 1999 through 2003. The success was hardly an overnight achievement. Groups worked for five years to educate Congress on research needs and the potential that scientific research offers to improve the quality of life of patients with neurological and other diseases. "When you have multiple groups bringing the same message to Congress, that's going to make an impact," says Rod Larson, director of the AAN's Center for Health Policy. "Many of the patient advocacy groups have legislative agendas that are very aligned with ours."

The AAN is a member of the Brain Attack Coalition, a non-profit group of organizations dedicated to fighting stroke, which is involved in a long-term effort to pass the Stroke Treatment and Ongoing Prevention Act (STOP Stroke Act). The Act authorizes a grant program to help states ensure that patients have

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access to quality stroke prevention, treatment and rehabilitation services. The Act also provides funds to create a statewide stroke awareness campaign, a stroke data registry, a clearinghouse for stroke information and a program to educate physicians on the latest stroke prevention strategies.

To ensure that neurologists can advocate for their patients' needs, the AAN teaches them advocacy skills through its annual Palatucci Advocacy Leadership Forum. The Forum teaches neurologists the keys to effective government relations and how to garner

attention from the news media. The AAN also works with partners on the state level to enact legislation that benefits those affected by neurological diseases, such as multiple sclerosis, Parkinson's disease and others. This summer the AAN shared a booth with patient advocacy groups at the National Conference of State Legislatures held in Seattle. Both physicians and patients need to keep a high profile in front of state lawmakers on issues such as the Medicaid program. As Larson sees it, cuts in federal Medicare funding will shift a greater share of the burden for medical costs to the states. Larson acknowledges there's a lot of competition for existing dollars on both state and national levels. "We want to make sure that any funding cuts don't hurt patients," he says. NN



The neurologists, shown here at the last Donald M. Palatucci Advocacy Leadership Forum, have a mission — to work on behalf of their patients for health care reforms on local, state and regional levels. The AAN leadership forum teaches participants to effectively negotiate government relations, form partnerships with other organizations to enact legislation that benefits those affected by neurological diseases and advocate for their causes by garnering attention from the news media.