

*National Multiple Sclerosis Society – California Action Network  
(MS-CAN)*

**GOVERNMENT ISSUES ACTION REPORT**

**Spring 2006**

**Legislative Issues Spark Spirited Dialogue at 6<sup>th</sup> Annual California NeuroAlliance Conference**

This year, the National Multiple Sclerosis Society was well represented at the 6<sup>th</sup> annual California NeuroAlliance Public Policy Conference held on March 27-28, 2006 at the Sheraton Grand Hotel in Sacramento. The conference agenda highlighted issues that have significant impact on individuals living with multiple sclerosis, including long term care, health insurance and off-label drug use. Participants asked insightful questions of speakers and engaged in lively debate on many of the issues, which provided attendees with important information for lobbying on the legislation with legislators and their staff in the Capitol on the following day. The four legislative initiatives that were the focus of this year's conference included:

**Informed Consent for Off-Label Use of Prescription Drugs** (AB 2856, Hancock)

**Nursing Home Resident Rights** (SB 1248, Alquist)

**Nursing Home Reform** (SB 1312, Alquist)

**High Deductible Health Care Coverage** (AB 2281, Chan)

**Informed Consent for Off-Label Use of Prescription Medication: MS-CAN and Cal NeuroAlliance Consumer Advocacy Helps Defeat AB 2856**

California Medical Association (CMA) lobbyist Francisco Silva discussed many concerns that health care providers and consumers have about Assemblywoman Loni Hancock's (D-Berkeley) bill, AB 2856 that requires doctors to verbally provide an extensive list specified information to patients before prescribing or administering off-label medications, i.e. not approved for use by the federal Food and Drug Administration. The audience, both patients and physicians, reacted with alarm to

the intrusion this bill would have in the doctor-patient relationship and the barrier it would create to consumers' access to the most effective medications. During the following day's advocacy in the Capitol, GRC Chair **Tammy Pilisuk** and Northern California Chapter President **Joanne Neuman** expressed the Alliance's concerns about the bill during a constituent visit to Assemblymember Loni Hancock. Clearly, this visit was a turning point for the bill, as Ms. Hancock's staff indicated that similar concerns raised by consumers could have a significant impact on the future of the bill.

After the conference, continued efforts of individuals from all the chapters and MS-CAN helped to defeat AB 2856. This bill was a high priority for MS-CAN because individuals with MS are treated with several drugs that are used off-label, including Aricept, Botox, Neurontin and Provigil. The California Medical Association, other health care provider and consumer groups, including MS-CAN, joined together to lobby in opposition to the legislation. The bill was headed to a hearing in Assembly Health Committee on April 18 when Assemblywoman Loni Hancock removed it from the committee's agenda. The reason for "pulling the bill" was the intense opposition from consumers. In addition, **Stewart Ferry**, MS-CAN Director of Advocacy and several other individuals from the National Multiple Sclerosis Society and the California NeuroAlliance had organized letter writing and calls to both the Health Committee members and Assemblywoman Hancock and were prepared to testify in opposition to the bill.

Although MS-CAN believes that informed consent is an important piece of all patient care, the information required in the bill would necessitate a longer office visit, which doctors say is not possible both in terms of time and reimbursement for the cost of the visit. These concerns threatened the ability of patients to receive the medications they need. People with multiple sclerosis have established relationships with their physicians and this bill would have placed restrictions and unnecessary requirements on that relationship.

**Nursing Home Rights and Reform.** Robert McLaughlin, consultant to Senator Elaine Alquist (D-San Jose), spoke about the Senator's goal to improve care for people living in nursing homes. She has introduced two bills, SB 1248 and SB 1312 to meet this goal. SB 1248 assures that all nursing home residents have the same rights, regardless of who is paying for their nursing home stay. Currently, residents whose payment source is Medicare or Medi-Cal have more rights guaranteed to

them by federal law than private-pay residents who reside in nursing homes that do not accept Medicare or Medi-Cal and whose rights rely solely on state law.

Mr. McLaughlin described SB 1312, a bill that Senator Alquist introduced in response to her frustration and concern about the lack of inspections of state laws in nursing homes. At a hearing last year, Sen. Alquist was told by the Department of Health Services (DHS) that DHS was not inspecting nursing homes for compliance to state laws. The Department uses an obscure state law, that exempts DHS from inspecting nursing homes for adherence to state laws, although DHS does conduct annual inspections of federal laws. SB 1312 removes the exemption from state law and ensures that the Department of Health Services will enforce the numerous nursing home reform laws that the Legislature has passed in the last 20 years.

**High Deductible Health Care Coverage.** Assemblywoman Wilma Chan (D-Oakland), Chairwoman of the state Assembly's Health Committee, provided her perspective on the national trend toward high deductible health plans (HDHP) and her concern about the negative impact the plans have on people with chronic health conditions. Her bill, AB 2281, is an attempt to establish some protections for individuals who have this type of health insurance. Although conference participants had differing views on the value of high deductible health plans, most people recognized the need to provide the public as much information as possible about these plans so that consumers can make informed decisions about choosing the best health insurance coverage.

Finally, Sarah Rogers, consultant to Senator Sheila Kuehl (D-Santa Monica), updated participants on SB 840, Senator Kuehl's proposal to establish the state government as the single payer for health insurance in California and SB 1784, the bill that establishes the financing mechanism for SB 840. Although the Alliance does not have a position on the single payer bill, Ms Rogers informed the group on the progress of the bills and expressed Senator Kuehl's views about their importance to reforming the current health insurance system.

### **MS-CAN Participates in Olmstead Workgroups**

The Olmstead Advisory Committee was created by the Secretary of the Health and Human Services Agency to guide the state's implementation of Olmstead in California. The 1999 Supreme Court's *Olmstead v. LC* decision requires states to assure that disabled people can live in the least restrictive environment. The goal of Olmstead is to assure home and community-based services to delay or prevent

institutionalization. Although a representative of the National Multiple Sclerosis Society was not selected as a member of the Olmstead Advisory Group, GRC members **Pam Hirshberg, Roy Glickman and Amy Van Meter** are monitoring the workgroup meetings and provide input, as necessary, to make sure that the NMSS priority - needs of the younger disabled - are taken into account in the planning process.

The Advisory Group was divided into three workgroups – assessment/transition (assessing individuals to determine who should go into nursing home care/transitioning individuals out of nursing home care), diversion (diversion of individuals from unnecessary use of institutional care) and data (determining who is at risk of institutionalization, who has the potential to transition from institutions into the community, and what services and supports are available to help individuals remain at home) – that are charged with formulating policy recommendations to the Advisory Group and the HHS Secretary.

The importance of monitoring the workgroups and the work of the Advisory group was underscored by Sarah Steenhausen, Assistant Secretary, Health and Human Services Agency, who spoke at the MS dinner on March 26, 2006, prior to the start of the California NeuroAlliance Conference. Ms. Steenhausen encouraged MS-CAN to add its voice through every avenue, including continuing participation on workgroup calls, and providing written recommendations to the Agency. She indicated that public input has been invaluable in helping to shape the Olmstead plan, thus far, for California.

### **Legislative Update**

The following summarizes the current status of the 2006 MS-CAN priority bills:

**AB 1112 (Cohn) Vehicles: disabled persons and disabled veterans: parking**

This bill would allow a disabled person or disabled veteran displaying the disabled plates or placards to park for unlimited periods in any available parking space in a publicly-owned facility, regardless of visible, posted vehicle permit requirements, except for parking in a space that is designated by a number, making, name, or title for a particular person or permittee.

**Bill Status:** Passed the Assembly. In Senate Transportation and Housing Committee

**MS-CAN Position: Support**

### **SB 1248 (Alquist) Resident Rights**

Existing law requires that skilled nursing and intermediate care facilities have established written policies to ensure that each patient admitted to the facility has certain rights and are notified of certain facility obligations. Currently, these requirements only apply to patients on Medicare or Medi-Cal, but not private pay. This bill provides equity in patient rights, regardless of payment source. Among those rights and obligations are: 1) the facility shall employ an adequate number of qualified personnel to carry out all of the functions of the facility; 2) a nurses' call system shall be maintained in operating order in all nursing units and provide visible and audible signal communication between nursing personnel and patients. Extension cords to each patient's bed shall be readily accessible to patients at all times. 3) If a resident of a long-term health care facility has been hospitalized in an acute care hospital, he or she has the right to return to the facility, per state or federal bed hold provisions; 4) the facility shall provide an activity program staffed and equipped to meet the needs and interests of each patient and to encourage self-care and resumption of normal activities.

**Bill Status:** On the Senate Floor

**MS-CAN Position:** Support

#### **SB 1312 (Alquist) Nursing Home Facilities: Inspections**

This bill removes language that the Department of Health Services states exempts it from annual surveys of enforcement of state laws in nursing homes and inserts language to reaffirm that the Department must enforce all state nursing home laws.

**Bill Status:** Passed Senate Health Committee on April 19, 2006

**MS-CAN Position:** Support

#### **SB 1353 (Romero) Medi-Cal: provider enrollment**

This bill will simplify the Medi-Cal provider application process and alleviate application backlog by reducing the time Department of Health Services has to process provider enrollment application. The intent of the bill is to reduce the number of physicians who are currently waiting to be enrolled in Medi-Cal, thereby resulting in greater patient access to Medi-Cal providers and health care services.

**Status:** Hearing in Senate Appropriations Committee on April 24, 2006

**MS-CAN Position:** Support

#### **AB 1930 (Berg) Prescription Drugs for Dual Eligibles in Skilled Nursing Facilities**

There is a significant problem with coverage of Part D drug benefits for dually-eligible residents of long-term care facilities who are admitted to a facility prior to applying for benefits, and are later determined to be retroactively eligible for both Medi-Cal and Part D benefits. While Medi-Cal benefits are available to the resident

retroactively, their prescription drug coverage through Medicare Part D is not. As a result, there is a gap in coverage from the date during the month for which Medi-Cal has determined to be the date of Medi-Cal eligibility and the first of the next month, when Part D benefits begin. AB 1930 will require the Medi-Cal program to cover the costs of prescription drugs for dual eligibles in long-term care facilities during the coverage gap from the resident's date of Medi-Cal eligibility until Medicare Part D benefits begin.

**Bill Status:** Being held in Assembly Appropriations Committee

**MS-CAN Position:** Support

**AB 2749 (Strickland) Home Improvement Loans**

This bill would require the Department of Housing and Community Development to establish a pilot program in Ventura and Los Angeles Counties to provide a revolving home improvement loan fund to make no-interest home improvement loans to qualified low- and moderate-income elderly and disabled persons.

**Bill Status:** In Assembly Aging and Long Term Care Committee

**MS-CAN Position:** Support

**AB 2856 (Hancock) Informed consent: prescription medication off-label use**

This bill would require a physician and surgeon to obtain informed consent from a patient before prescribing, administering, or furnishing a prescription medication for an off-label use, and specifies the information that a physician is required to *verbally* provide in order to obtain the patient's informed consent.

**Bill Status:** Author pulled bill from hearing agenda. Presumed dead.

**MS-CAN Position:** Oppose

**SB 300 (Kuehl) Family and Medical leave.**

This bill expands the current Family and Medical Leave Act by allowing an employee to take protected leave to care for his or her independent adult child or a parent-in-law suffering from a serious health condition, and permits an employee to take leave to care for a seriously ill grandparent, sibling, or domestic partner.

MS-CAN actively supported the Family and Medical Leave Act in 2002 that established the benefit.

**Bill Status:** In Assembly Appropriations Committee

**MS CAN Position:** Support

**SB 1338 (Alquist) California Health Care Infrastructure Authority**

This bill would require the Health and Human Services Agency to develop a plan to establish an electronic health care record for every Californian.

**Bill Status:** Passed Senate Health Committee on April 19, 2006

**MS-CAN Position: Support**

**SB 1451 (Kehoe) Emergency preparedness, planning, and information**

This bill would provide that the State Fire Marshal shall convene a permanent advisory committee to make recommendations to the State Fire Marshal, the Legislature, and appropriate state and local agencies regarding preparedness, planning, procedures, and the provision of accessible information relating to the emergency evacuation of designated groups from public and private facilities and private residences during emergency or disaster situations. Among the members of the advisory committee are persons with physical, developmental, learning and cognitive disabilities.

**Bill Status:** Hearing in Senate Appropriations Committee on April 24, 2006

**MS-CAN Position: Support**