

## Fampridine-SR may be first drug marketed for MS symptom

Last October, the first drug specifically for an MS symptom was recommended by an FDA panel for approval.

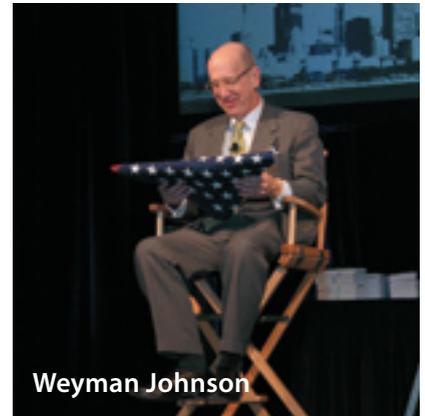
After an all-day meeting, the panel found Fampridine-SR (with the proposed brand name Amaya) to be effective in improving walking speed in people with MS. The panel heard testimony from individuals and patient advocacy groups, including the National MS Society. “There has been no other drug, experimental or approved, that has had such a positive impact on my ability to walk,” said E.J. Levy, diagnosed in 2002.

At press time, the FDA was expected to make a final decision on whether to approve the drug for marketing in late January, although that date is provisional.

At present, there is no drug treatment available specifically for treating MS-related walking issues. To stay tuned on the agency’s decision, check News on our homepage at [nationalMSsociety.org](http://nationalMSsociety.org).

## Thomas Kuhn takes the helm

The National MS Society has a new volunteer leader, Tom Kuhn of Washington, D.C., who accepted the position of chair of the National Board of Directors on November 5 at the Leadership Meeting in Chicago. Kuhn, who is a long-time Society member and former chair of the National Capital Chapter’s Board of Trustees, brings a deep knowledge of marketplace economics and organizational dynamics to the Society. “Organizational effectiveness”—his forte—may sound dry but it translates into better nationwide programs, more carefully targeted research,



Weyman Johnson

more dynamic fund-raising efforts.

Kuhn’s skills are evident in his professional life as president of Edison Electric Institute, a Washington consortium representing the nation’s electric power companies.

The Chicago meeting was graced with a spirited farewell to Weyman Johnson, who has served as chair of the National Board for four years. Johnson was presented with a special U.S. flag and the warm affection of all.

## Society Moves It! at Leadership Meeting

Like MS and Walk MS team captains, top volunteer leadership and Society staff Moved It! at the Society’s November Leadership Meeting in Chicago. They celebrated successes and shared inspiration in workshops, special sessions and fun events.

Phil Keoghan, host of CBS’s *The Amazing Race*, welcomed the crowd with a rousing keynote



From left, Joyce Nelson, PepsiCo national team captains Jennifer Johnson and Bryan Cleal, and Thomas Kuhn.



speech about his philosophy of “No Opportunity Wasted.” Keoghan, who cycled across the U.S. last year to benefit the Society, also spent time autographing copies of his book of the same title for fund-raising champions and Bike and Walk MS team captains. Country music star Clay Walker, diagnosed with MS in 1996, got feet tapping in a special concert, a celebratory parade kept spirits high and an MS research panel answered audience questions about MS. Attendees got an information boost in workshops on using social media, building bigger teams, and leadership. A marching band sent everyone home ready to move toward our shared goal—a world free of MS.

## As states slash, activists get creative

**S**tate budgets define and invest in the programs and services

the state deems valuable. But due to the economic downturn, many states had to make significant cuts.

In 2009, many states made tough decisions and eliminated millions from Medicaid, including payments to doctors who treat Medicaid patients. Other states reduced community support services by millions for seniors and people with disabilities.

### What lies ahead

In FY 2010 state budgets don't look much better. According to the National Conference of State Legislatures, 36 states are still projecting shortfalls in the current fiscal year. (For most states, the current fiscal year runs from July 2009 through June 2010.) Budget proposals for fiscal year 2011 are just as bad.

### What can be done?

Creative approaches include “unfunded legislative direction,” which is sometimes inserted

during budget deliberations. States can establish a program or service, and wait to seek funding for it for another year. This at least gets an initiative on the books. Advocates are also pushing more states to pursue an MS income tax check-off, which costs nothing.

For big issues, MS awareness helps. Find out what you can do in your state. Call 1-800-344-4867 or visit [nationalMSsociety.org/chapter](http://nationalMSsociety.org/chapter). Ask about activities for MS Awareness Week, March 8–14.

## MS activists go to Washington, D.C., this March

**F**rom around the country, volunteers will gather March 1–3 in Washington for the Society's 19th annual MS Public Policy Conference. The activists plan to urge Congress to increase federal funding for MS research through the Congressionally Directed Medical Research Programs (CDMRP), administered by the Department of Defense. They achieved a huge win in 2009 when the CDMRP awarded \$5 million to MS research. Now they plan to build on that success, asking for an increase to \$15 million.

To stay up to date on the activists' progress, visit [nationalMSsociety.org/advocacy](http://nationalMSsociety.org/advocacy) and [msactivist.blogspot.com](http://msactivist.blogspot.com).