



**National
Multiple Sclerosis
Society**

Connecticut General Assembly – Labor and Public Employees Committee
Public Hearing – February 14, 2019

Testimony of Laura Hoch
Manager of Advocacy, National Multiple Sclerosis Society

Senator Kushner, Senator Miner, Representative Porter, Representative Polletta and members of the Labor and Public Employees Committee, thank you for the opportunity to provide testimony on Senate Bill 1, An Act Concerning Paid Family and Medical Leave and House Bill 5003, An Act Implementing A Paid Family Medical Leave Program, and how they may affect those who live with multiple sclerosis (MS) and their families.

The National MS Society supports paid family and medical leave legislation that would allow workers to continue earning a portion of their pay while they take time away from work to address a serious health condition, care for a family member with a serious health condition, or care for a new child.

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary and range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS.

At some point in their lives, people living with MS may need time away from work to deal with a serious illness, or their family members may need time away from work to care for them. The federal Family and Medical Leave Act (FMLA) provides important unpaid job-protected leave. However, fewer than 40 percent of workers in the U.S. have access to personal paid medical leave through employer-provided short-term disability insurance, which means many people cannot afford to take leave when they need it.

Most people with MS are diagnosed between the ages of 20 and 50—prime working years. People living with MS often continue working long after their diagnosis, but some may need time away from work to manage an unexpected change in health. Many workers may need to take a medical leave at some point during their lifetime. In fact, 55% of leaves taken under the FMLA were for a worker's own illness; another 18% were for caregiving for a sick family member.



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For those who must take time off without pay, it can be challenging to make ends meet, as the average cost of living with MS, including both direct and indirect expenses (e.g. healthcare costs, lost wages), is upwards of \$70,000 per year, per person.

Caregivers face financial challenges and are too often forced to choose between work and caregiving because they lack access to paid leave. An estimated 43.5 million adults in the U.S. provide unpaid caregiving. These family caregivers are the predominant providers of long-term services and supports for people with illnesses or disabilities. Among caregivers who take time off for caregiving, 48% report losing their income. Low-wage workers are hit particularly hard, because they are the least likely to have access to any type of leave, even though they are the most in-need of policies that help them prevent financial catastrophe when illness strikes.

We support legislation that would create a paid leave program for a serious health condition; to care for a family member with a serious health condition; to care for a newborn, newly-adopted, or newly-placed foster child. We look forward to working with the Committee on the direction of such important public policy. Thank you for this opportunity to submit comments on this bill. If you have any questions or would like to discuss these comments further, please feel free to contact Laura Hoch, Manager of Advocacy at laura.hoch@nmss.org or (860) 913-2550 X52521.