



Maine State Legislature – Committee on Labor and Housing  
Public Hearing – May 25, 2023

Testimony of Laura Hoch

Senior Manager of Advocacy, National Multiple Sclerosis Society

LD 1964 – An Act to Implement the Recommendations of the Commission to Develop a Paid Family and Medical Leave Benefits Program

Chair Tipping, Chair Roeder and members of the Committee on LD 1964, An Act to Implement the Recommendations of the Commission to Develop a Paid Family and Medical Leave Benefits Program, and how they may affect those who live with multiple sclerosis (MS) and their families.

MS is an unpredictable disease of the central nervous system. Currently there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes and vision issues. An estimated 1 million people live with MS in the United States. Early diagnosis and treatment are critical to minimize disability. Significant progress is being made to achieve 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, just over 40% 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 medical leave at some point during their lifetime. In fact, over 50% of leaves taken under the FMLA were for a worker’s own illness; another 20% were for caregiving of a sick family member<sup>1</sup>. For those who must take time off without pay, it can be nearly impossible to make ends meet. MS is an extremely expensive disease. The average total cost of living with MS is \$88,487 per year<sup>2</sup>.

---

<sup>1</sup> <https://nationalpartnership.org/our-work/resources/economic-justice/paid-leave/key-facts-the-family-and-medical-leave-act.pdf>

<sup>2</sup> Bebo, Bruce et. al. The Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. *Neurology* May 2022, 98 (18) e1810-e1817; DOI: 10.1212/WNL.000000000000200150. <https://n.neurology.org/content/98/18/e1810> (accessed May 4, 2022).



**National  
Multiple Sclerosis  
Society**

Caregivers also face financial challenges and are too often forced to choose between work and caregiving because they lack access to paid leave. An estimated 40 million adults in the U.S. provide \$470 billion per year in unpaid caregiving<sup>3</sup>. These family caregivers are the predominant providers of long-term services and supports for people with illnesses or disabilities. 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.

Given the disproportionate impact on low-wage workers, we applaud this legislative body for including language that addresses this and note that it is critical to keep in provisions such as the 90% benefit up to 120% of the state's average weekly wage. Additionally, many people living with chronic conditions create their own communities outside of the bounds of traditional families. This is why we commend the legislative language around the definition of family and extending it to significant personal bonds that are like family, regardless of biological or legal relationship.

One concern we have with the current language is the determination of weekly earnings. The bill outlines a process by which the authority would average the previous four quarters of earnings. This may leave people who were not previously working – or who previously worked a much lower wage job - but have been working for the required minimum of two quarters to receive a fraction of what they otherwise could and much less than they would need to support themselves. We would instead encourage policy to reflect an employee's current salary, so long as they have been working for the required two quarters.

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 and therefore support the passage of LD 1964 by this Committee. If you have any questions or would like to discuss these comments further, please feel free to contact Laura Hoch at [laura.hoch@nmss.org](mailto:laura.hoch@nmss.org) or (475) 400-0870.

---

<sup>3</sup> <https://www.aarp.org/research/topics/care/info-2015/national-survey-family-caregivers.html>



**National  
Multiple Sclerosis  
Society**