



Comments regarding House Bill 839: Time to Care Act

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The National Multiple Sclerosis Society appreciates the opportunity to submit written comments in support of House Bill 839 – the Time to Care Act. We thank Delegate Valderrama for bringing this important bill forward.

Multiple sclerosis (MS) impacts nearly 1 million people in the United States. It is an unpredictable, often disabling disease of the brain and spinal cord that interrupts the flow of information from the brain to the body. Symptoms 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. The cause is unknown and there is no cure.

Most people with MS are diagnosed between the ages of 20 and 50 which are prime working years. People living with MS often continue working long after their diagnosis, but some may need time away from work to manage what can be a serious health condition. Additionally, 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 United States (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.

For those who must take time off without pay, it can be challenging to make ends meet. 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. Unpaid time off may often lead to financial devastation.

The Time to Care Act would be especially beneficial for Caregivers. 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 and nearly 800,000 in Maryland.¹ Of the adults who use FMLA, 18% took unpaid time off to care for

¹ AARP. *New Maryland Family Caregivers Survey Released by AARP*. 10 Mar. 2016, states.aarp.org/md-new-maryland-family-caregivers-survey-released-by-aarp/.

a sick family member. These family caregivers are the predominant providers of long-term services and supports for people with illnesses or disabilities.

According to AARP's State of the Caregiver report, 6 in 10 caregivers have experienced at least one impact or change to their employment situation as a result of caregiving such as cutting back on their working hours, taking a leave of absence or receiving a warning about performance or attendance.² It is also important to note that caregiving comes at a cost. AARP estimates that caregivers spend an average of \$7,000 out of pocket on caregiving related expenses each year.³ The Time to Care Act would provide an opportunity for caregivers take leave without facing financial ruin.

For these reasons, the National MS Society urges you to favorably report House Bill 839 so that a paid leave program can be established in Maryland. If we can be of any assistance as you move forward on this and other issues, please contact me, Shannon Wood, at shannon.wood@nmss.org.

² AARP, National Alliance for Caregiving. *Caregiving in the U.S. 2015 Report*

³ Rainville, Chuck, et al. *Family Caregiving and Out-of-Pocket Costs: 2016 Report*. 2016.