



**National
Multiple Sclerosis
Society**

February 1, 2017

Representative Dan Hawkins, Chair
House Health and Human Services Committee
Re: HB 2031 Proponent

Chair Hawkins and Committee Members:

I am here today to testify on behalf of the National Multiple Sclerosis Society in support of House Bill number 2031, which is a bill that would establish a palliative care and quality of life interdisciplinary advisory council and a palliative care consumer and professional information and education program. I provide this testimony to you as director and founder of the KU Center for MS Care, and National MS Society Health Advisory Committee Chair. I am a professor in the department at the University of Kansas Medical Center, but I am not speaking on behalf of KUMC at this time.

Multiple Sclerosis is an unpredictable, often disabling disease of the central nervous system, which interrupts the flow of information within the brain, and between the brain and 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. While many patients with MS never develop severe disability from their disease, some become quite disabled over time.

The National MS Society is working to increase access to high quality, comprehensive and coordinated care that promotes overall health and wellness, reduces complications, and optimizes independence, safety, participation, and engagement. We also want to assist family members and other support partners in their efforts to provide safe and optimal care for their loved ones while also attending to their own health and well-being. H.B. 2031 advances our mission by promoting overall health and wellness and helping to provide safe and optimal care for people living with MS.

Clinicians who specialize in palliative care excel at intensive symptom and pain management with a focus on enhancing the patient's quality of life and caregiver well-being. Discussing advanced care options, including palliative care, can often be difficult for both patients who are living with a chronic condition as well as their clinicians. Due to this, people who are living with MS often do not receive the resources or guidance that they need in order to appropriately plan their advanced care needs. Sometimes a person who specializes in these advanced care options can be very helpful in guiding patients and their care-givers in making these difficult decisions.

We often talk about dying with MS rather than dying from it. Due to advances in biomedical research, people who have been diagnosed with MS are living longer lives, but on average they still live up to 10 years less than the normal lifespan. This can be due to a number of conditions. These include sepsis, caused by recurrent or



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severe acute infections like urinary tract infections or aspiration pneumonia, pressure sores, respiratory insufficiency from a weakened diaphragm and accessory muscles that support respiration, and suicide, which are directly related to MS, as well as heart disease, cancer, and kidney failure which are not as directly related, but can be associated with inactivity or the medications used to treat MS. People with MS also suffer from the same diseases as anyone else, but often they are coping with disability from the MS in addition to another life threatening illness. Sometimes their severe disability will become much more severe when they are acutely ill, and become less severe when they recover, making judgment as to the terminal nature of their condition very difficult. Good expertise is needed to help MS patients and their families to understand these changes. MS patients need open and timely access to resources concerning palliative care so that they can adequately prepare both themselves and their family for advanced care planning. Additionally, they need access to palliative care specialists to alleviate the symptoms of MS when they are at their worst.

H.B. 2031 would move the needle significantly forward in Kansas. This bill would establish a palliative care and quality of life interdisciplinary advisory council within the department of health and environment. This council will develop recommendations and will advise the department of health and environment on matters related to palliative care and evaluate palliative care initiatives in the state. Additionally, it would evaluate the effectiveness of the palliative care consumer and professional information and education program. This will bring much-needed clinical expertise about palliative care to the department of health and environment and will ensure that the state of Kansas is providing as much end-of-life support as possible to people who are living with incurable chronic conditions like multiple sclerosis.

Specifically, the state palliative care consumer and professional information and education program will maximize the effectiveness of palliative care initiatives in the state by ensuring that comprehensive and accurate information and education about palliative care is available to the public, healthcare providers, and healthcare facilities. Additionally, the department of health and environment will be instructed to publish information on its website, including links to external resources about palliative care. This information will include continuing education opportunities for healthcare providers, information about palliative care delivery in the home and other environments, and consumer education materials and referral information for palliative care. This information will be invaluable for both patients and clinicians as it will both inform consumers and help erode the stigma around discussing end-of-life planning.

Thank you again for giving me the opportunity to testify in support of this bill. In closing, I would like to respectfully urge the committee to support HB 2031 for consideration in the House of Representatives.

Sincerely,

Dr. Sharon Lynch
Health Advisory Committee Chair,
National MS Society