Committee on Health and Human Services
c/o Kerri Withee
Cross Building, Room 209
100 State House Station
Augusta, ME 04333

Re: LD 296: *An Act to Provide a Tax Credit for Family Caregivers*

Good morning, Senator Claxton, Representative Meyer, and esteemed members of the Joint Standing Committee on Health and Human Services.

My name is Kristin Lash, I am a resident of West Bath and voter with a background in health care services. For over 11 years I provided informed, therapeutic massage therapy in wellness and clinical settings including palliative and hospice care. I am currently pursuing my Masters of Social Work and I am here today to testify in support of LD 296.

Illness affects individuals and families, biological or chosen, in different and unique ways yet there are some common, reported experiences among informal and family caregivers: they give up careers and possibly experience financial strain or they continue to work while balancing new demands that come with new diagnoses. From what I have witnessed personally and professionally, caregivers also experience the sudden or slow release of expectations, routines, and even roles that once defined their lives. LD 296 recognizes this process and sacrifice.

According to the AARP, approximately 181,000 Mainers in 2017 identified as family caregivers and provided 152 million hours of unpaid care and labor equivalent to 2.2 billion dollars. At the national level, 1 in 4 caregivers are women and more than half of all caregivers provide assistance beyond 24 months; those numbers have likely increased since the COVID-19 pandemic. Research shows caregivers experience an increase in strengthened relationships and personal satisfaction due to altruism but additional studies also find they experience increased financial, emotional, and personal health strain. A June 2020 CDC survey reported a 27 percent increase in suicide ideation among family and informal caregivers.

My great aunt Marion was the sole caregiver for my great uncle Fran for over 20 years, accepting only minimal help toward the end to do errands or go to church. She was poised, private, and to be honest, I can’t remember her laugh but she was incredibly kind. I know she loved my uncle deeply, but I also know she was sad, lonely at times, and extremely tired. It was palpable.

I only knew my great-uncle Fran in the progressed stages of multiple sclerosis, which confined him to a hospital by his early 50s. I also knew him to be warm and generous. I remember running around the corner of the fireplace that separated the living room from his living space; his bright blue eyes holding me in a hug because he could no longer lift his arms. As a kid, I thought he lucked out and had the best view of the whole place with large windows opening up to the gardens my aunt tended.

Illness is a lot like the memory of children. It can lock individuals and their identities into a fixed place. Time and events are grouped by what came before and what came after diagnosis. I naturally wondered what time felt like for my Uncle Fran, who was visibly restricted by his MS. I also wondered how my Aunt Marion experienced time. Able-bodied and healthy yet suspended in a liminal state. Her identity, daily tasks, ability to plan for a month let alone years into the future was eclipsed by the frailty yet persistence of Uncle Fran's life. I wondered what the late night and early morning hours held for her. She slept in the bedroom they once shared, but I wonder if and when she ever rested.

I met my Aunt Marion again, as an adult. I found her the kitchens, living rooms, and quiet spaces of the homes I visited as a hospice massage therapist. Sometimes she was quiet, having not slept through the night. Sometimes she surprised me with her energy and desire to talk, wanting to fill the room with stories a parent or partner could no longer voice. Most often, she remained close to the bedside despite the influx of help, as if she knew it was only temporary.

My aunt Marion's life, like many other family and informal caregivers, became defined by the care she provided over those 20 years. Whole generations are defined by that amount of time. We build retirement wealth in careers that span 10 to 20 years and longer, if we're lucky. Family caregivers enter into multi-year, sometimes open contracts because they believe in their investments or because they have no other option yet their career commitment to care goes unrecognized in so many ways.

We need to create better support systems for individuals who occupy support roles. We need to care for our caregivers and help them maintain their own quality of life, which they so often put aside for their loved ones. LD 296 is an opportunity to tell our family caregivers that we not only see their physical and emotional labor and sacrifices, but we deeply value them as individuals and we value their contributions.

I ask you to vote "ought to pass" on LD 296 so family and informal caregivers like my Aunt Marion are recognized for their vital roles and are afforded an opportunity to rest.

Thank you,

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