March 25, 2019

To: The House Business and Labor Committee and the Senate Workforce Committee
From: Katy Liljeholm
Re: Support of HB 3031

Dear Chair and Members of the Committee,

My name is Katy Liljeholm and I'm here tonight with Family Forward Oregon and I live in Portland.

On March 6th, 2017, I went to bed perfectly healthy. On March 7th, 2017, I woke up, got up to turn off the alarm clock, and immediately collapsed, unable to move the right side of my body or to speak. Though I regained the power of speech and movement quickly, my collapse initiated a cascade of slowly increasing symptoms that have been impossible to treat and control. Though I was rushed to the ER, with measurable brain damage in my MRI scans, and have seen many specialists, my illness currently eludes diagnosis. This is not uncommon. I have a friend with MS who spent ten years trying to get her diagnosis, a friend and fellow mother with Lupus who waited 17 years between onset of her disability and her first positive test result. I have a friend who had a tumor in her cheek and it took 8 months to get her diagnosis. When actress Selma Blair brought her cane to an Oscars party, gathering attention to her condition of MS, she told reporters she first experienced pain and fatigue and mobility issues when her son was born, but did not receive a diagnosis until her son was 7. Parents spend years being ill without treatment.

My family has had to do what the medical community has been unable or unwilling to do for me: care for my illness and keep our family together. Because I have no treatment, rest and quiet have become the primary pillars of my care: difficult for the mom of six year old twins and a three year old to come by. An essential component of that has been the extreme flexibility my husband's employer has given him. When my symptoms are too severe drive our youngest to preschool, or to take care of our twins sons when they have a day off from school, he's the one who calls in late, or leaves early, or works from home, or doesn't work at all. My body doesn't give me notice, so he is unable to give work notice. Our experiences with doctors have been fraught. He takes off work to go with me to doctors appointments, to advocate for me and to help me remember my questions or my list of symptoms. He spends hours on the phone trying to track down lost referrals to specialists or to ask for new tests. Our sons are adopted, and soon after adoption, lost their foster father to a brain disease. My illness is an emotional burden for my young sons, who have already experienced attachment traumas and loss. So my husband takes off work to take them to counseling and to occupational therapy. When they get the normal sniffles and fevers of childhood, my husband takes off work to take them to the doctor. When they get in trouble at after school daycare, my husband takes off work to pick them up to bring them home. My husband is often unwilling to go to the doctor, or go to counseling for himself, because he is afraid to take more time off work.

His boss has told him to do what he needs to do to take care of his family. Many Oregonians are not so lucky. If we didn’t have the support of my husband’s workplace, my health would likely be much worse and my sons and I would all be struggling to cope. Family steps in where the system fails us. The system has to support family in doing that. I hope that Oregon can lead the way, set an example for the country. When the chips are down, family matters.

Sincerely,

Katy Liljeholm