

Employee Autoimmune Disorder Protection Act Testimony

March 6, 2024

Hello,

My name is Alexandra McOwen and I am one of the 1.5 million Americans living with lupus, an autoimmune disease in which your body's immune system mistakenly attacks its own systems and organs and can take an average of 7 years to properly diagnose. Lupus can cause a multitude of serious symptoms and I was diagnosed with lupus at age 24 with 3 blood clots, including a stroke, joint pain, debilitating fatigue, anemia, and memory problems.

Lupus is defined by periods called "flares" which are times where symptoms worsen. Flares are caused by different things for different people, but mine are mainly caused by high stress which can sometimes be associated with work. When I have a lupus flare, I have debilitating fatigue, joint pain, and muscle tension and the flexibility to work from home allows me to preserve my energy throughout the day and more easily and successfully manage my sometimes unpredictable symptoms.

The flexibility to work from home as needed also allows me to reduce unnecessary exposure to other illnesses which I am not able to fight off as easily. Catching a contagious illness in the office could cause a lupus flare which could leave me unable to work for periods much longer than if my immune system functioned normally.

Finally, I want to emphasize that I, along with others with autoimmune diseases, live with a heightened sense and awareness of our health and wellness. One thing that is often misunderstood about autoimmune disorders is that taking care of ourselves is a full time job and requires a full toolbox - even if we may not look sick. I pride myself in playing an active role in my healthcare and maintaining my wellness which is part of my daily routine. My toolbox includes a team of doctors that I see regularly, taking medication, getting enough rest, weekly blood testing, eating well, and stretching among other things. Having added flexibility to work from home as needed provides autoimmune patients with an additional tool they can use to focus their sometimes limited energy to continue to contribute to society and make a difference in their communities.

I am thrilled to see the introduction of the Employee Autoimmune Disorder Protection Act in Maryland and hope that you vote in support of this important bill to protect many like myself who battle with chronic autoimmune diseases.