

**Chairman Mathews, Vice-Chairman Stewart, Ranking Member Liston and members of the Public Health Policy Committee.**

**Good morning.**

**My name is Suzanne Brown and I am here this morning to testify in support of HB 538 designating the month of May as Lupus Awareness Month.**

**Why am I supportive of HB 538? Because I am a Lupus Warrior. I was diagnosed with SLE (one of the 4 different forms of Lupus) approximately seven years ago after battling symptoms for several years. But I'm not alone in this fight.**

**1.5 million Americans have a form of lupus. Lupus strikes mostly woman – 9 out of 10 adults with lupus are women. Most people with lupus develop the disease between ages 15-44. People with lupus can experience significant symptoms such as pain, extreme fatigue, hair loss, cognitive issues and physical impairments that affect every facet of their lives. Many suffer from cardiovascular disease, strokes, disfiguring rashes and painful joints. For others, there may be no visible symptoms. People often say to me upon learning I have lupus, "You don't look sick." But I suffer with painful joints and fatigue on a daily basis. These symptoms, along with others, are exacerbated when I am experiencing a "flare."**

**There are also many challenges to reaching a lupus diagnosis. Lupus is known as "the great imitator" because its symptoms mimic other illnesses. On an average, it takes nearly 6 years for people with lupus to be diagnosed from the**

time they first notice their symptoms. Most people with lupus report being incorrectly diagnosed. One in 3 patients suffer from multiple autoimmune diseases. You're looking at one of them!

You may be asking yourself, but can people die of lupus? It is believed that 10-15 percent of people with lupus will die prematurely due to complications of lupus.

A study funded by the Lupus Foundation of America found that overall, lupus was among the top 20 leading causes of death in females ages 5-64. Among black and Hispanic women, lupus ranked 5<sup>th</sup> in the 15-24 years, 6<sup>th</sup> in 25-34 years, and 8<sup>th</sup> in the 35-44 years age groups.

## **AWARENESS**

While lupus is a widespread disease, awareness of the disease lags behind many other illnesses. In a survey conducted in 2019 by the Lupus Foundation of America, 63% of Americans have never heard of lupus or know little or nothing about the disease and its symptoms beyond the name - indicating there is significant opportunity and need for continued public education. This bill will be but one important step in creating the much-needed awareness.

I want to thank Rep. Upchurch and Rep. Brown (my wonderful and supportive husband of 33 years) for bringing this bill forward.

On behalf of my fellow lupus warriors – I urge a “yes” vote on this bill as another step in bringing awareness to this chronic disease.

