Good Morning (Afternoon) Chairman Dolan, Vice Chair Burke, Ranking Member Sykes and members of the Senate Finance Committee. I am grateful to appear before you today at this important hearing.

My name is Adrienne Fernandez. For the past six and a half years I have been an employee of the Lupus Foundation of America, Greater Ohio Chapter. I stand here today not only as an employee, but also as a patient who is passionate about what the organization does for lupus patients across Ohio.

Lupus is a disease that is unpredictable, uncontrollable at times and can wreak havoc on a patient’s body. The Mayo Clinic describes lupus as, “a systemic autoimmune disease that occurs when your body's immune system attacks your own tissues and organs. Inflammation caused by lupus can affect many different body systems — including your joints, skin, kidneys, blood cells, brain, heart and lungs. Lupus can be difficult to diagnose because its signs and symptoms often mimic those of other ailments.” (1)

Based on population estimates, it is believed that there are approximately 60,000 Ohioans and 1.5 million Americans living with a form of lupus. As mentioned before, lupus is difficult to identify, and takes - on average - six years to diagnose. This leaves many patients living in a state of high disease activity for many years without appropriate treatment. Unfortunately, this leads to irreversible damage to their bodies.

A recent study led by UCLA researchers found that lupus was among the top leading causes of death in females ages 5-64 and was the fifth ranked cause of death among black and Hispanic women ages 15-24, after excluding the three common external injury causes of death from analysis. (2)

Across the board, lupus remains poorly understood and underfunded. Lupus is a concerning public health issue and more funding is needed to provide education, teach preventive measures, educate frontline responders, conduct extensive research to identify the causes and cure of the disease, and increase public awareness so that potential lupus patients can seek treatment prior to when life threatening consequences occur.

In 2016, the state of Ohio recognized lupus as an important public health issue and asked the Ohio Department of Health to conduct a Lupus Needs Assessment. RAMA Consulting and the Lupus Foundation of America, Greater Ohio Chapter were charged with conducting the Lupus Needs Assessment which revealed the personal and public burden of lupus in Ohio. With further funding, we were able to successfully complete one of the five recommendations of the Lupus Needs Assessment, which was to educate first responders. We did this through the creation and implementation of a CME/CEU program for healthcare providers. The program was successful, however, there are still four incomplete recommendations. With further funding, the Lupus Foundation of America, Greater Ohio Chapter will be able to complete the following three recommendations;

1. Promote awareness of existing lupus educational and community resources for both patients and providers.
2. Develop targeted outreach strategies to more effectively engage minority communities in lupus research and support services.
3. Develop patient navigators who can provide patient education and assistance while connecting with necessary support services.

We are asking the senate to consider funding in the amount of $750,000 annually to be given to subject matter experts, the Lupus Foundation of America, Greater Ohio Chapter for the purpose of Lupus Education, Awareness, and Prevention (L.E.A.P.) and to complete the Ohio Lupus Needs Assessment recommendations.

When considering the importance of funding Lupus Education, Awareness, and Prevention programs in the state of Ohio, please keep in mind these key facts; 1 in 3 lupus patients have been temporarily disabled by the disease; 1 in 4 receive their healthcare through a government sponsored program such as Medicare or Medicaid; the cause of lupus remains UNKNOWN; there is NO cure and; only one medication has been developed specifically to treat lupus in the past 55 years. Lupus patients are relying on us to provide necessary support while they wait for a diagnosis and pray for a cause and a cure to be found. On behalf of the 60,000 Ohioans with lupus, I strongly urge you to consider this funding request. I welcome any questions you may have and thank you for your time.

1. Mayo Clinic Staff. 2017, Oct 25. Lupus Symptoms and Causes. Retrieved from URL;  <https://www.mayoclinic.org/diseases-conditions/lupus/symptoms-causes/syc-20365789>*.*
2. Yen EY, Singh RR. [**Brief report: Lupus—An unrecognized leading cause of death in young females: A population‐based study using nationwide death certificates, 2000–2015**](https://www.ncbi.nlm.nih.gov/pubmed/29671279). *Arthritis Rheumatology*. 2018 Aug;70(8):1251–1255.