

Good morning, Chairman Cirino, Vice-Chair Chavez, Ranking Member Hicks-Hudson, and Members of the Senate Finance Committee.

Thank you for the opportunity to provide testimony today. My name is Adrienne Fernandez, and I'm an employee of the Lupus Foundation of America, Greater Ohio Chapter. I also happen to be a lupus patient. Do I look sick? Generally, no. But I assure you that I live with the consequences of having lupus daily.

I know most of you have spoken with us and know what lupus is. However, for those unfamiliar, I'll give you a brief description. Lupus is a chronic autoimmune disease that can cause inflammation and pain in any part of the body, including organs. It's heterogeneous, meaning each patient looks different. It can be mild or severe enough to cause death.

Our job at the LFA is focused on improving the quality of life for all people impacted by lupus through programs of research, education, support, and advocacy. We're also committed to reducing the personal and public burden of lupus. The results of the first-ever statewide Lupus Needs Assessment conducted in 2016 revealed that much work still needs to be done.

I'm sure in your role as a legislator, you must ask difficult questions. Why is this issue important? Why should we provide funding for this? As I thought about my testimony, it led me to consider why lupus should be important to our legislators here in Ohio. After all, many diseases impact Ohioans.

So, why is lupus funding important to the state of Ohio?

1. **Lupus is not a season.** We don't know the cause, and there's no cure. Medications to treat lupus are getting better, but it's still chronic. Meaning it will never go away. There's nothing I, as a patient, can do to change this. I will always have lupus.
2. **The symptoms and consequences of lupus can devastate a person's life.** Patients can be disabled, on dialysis, recovering from kidney transplants, impacted by strokes and other Central Nervous System issues, and struggling with repeated infections due to their suppressed immune system.
3. **Lupus impacts almost every facet of a person's life.** The average annual total costs for people with lupus can be as high as **\$50,000**. Up to **55%** of lupus patients reported a complete or partial loss of their income because they are no longer able to work full-time due to complications of lupus. **One in three patients** have been temporarily disabled by the disease. **One in four** currently receive disability payments and receive their healthcare through a government-sponsored program such as Medicare and Medicaid.

4. **Women are estimated to be 9 to 10 times more likely to develop lupus than men**, particularly women of childbearing age. It is more common in minorities. It's also important to note that some research suggests that veterans may be at a higher risk of developing lupus compared to the general population, potentially due to factors associated with military service.

So, how does our organization help reduce the personal and public burden of lupus? We provide educational programs on how to live a better quality of life while managing a chronic illness, including helping patients get back to work if they are able. We remove barriers to care such as transportation to doctor's appointments, reducing medical costs, providing mental health assistance, and ensuring patients have access to food. We have a network of patient navigators who work with lupus patients regarding self-management. We also provide CME/CEU training to medical and community healthcare workers to help reduce the time to diagnosis. Most importantly, we provide the support necessary to navigate this medically complex disease.

We provide an incredible amount of support to our lupus patients throughout the state. However, until we discover the cause and find the cure for lupus, we continue to have an uphill battle. We need to strengthen our resolve to end lupus. We need to ensure that every single Ohioan with lupus doesn't suffer in silence. And we need the Ohio Senate's support.

Our funding, we believe, was inadvertently removed from the House Budget. We respectfully ask the Senate to reflect Governor DeWine's executive budget and again include the Lupus Foundation of America, Greater Ohio Chapter, for the purpose of funding the lupus education and awareness program.

Thank you, and I welcome any questions you may have.