

Members of the Senate Health Committee,

It is an honor to provide written testimony to this important Committee. My name is Adrienne Fernandez, I am a lupus patient who for the past 12 years has worked for the Lupus Foundation of America, Greater Ohio Chapter. We are an affiliated Chapter of the Lupus Foundation of America which was founded in 1977 as a national voluntary health organization based in Washington D.C. The Foundation is dedicated to improving the quality of life for all people affected by lupus through programs of research, education, support and advocacy.

Due to our advocacy work and the positions that you hold, most of you already know what lupus is. As a heterogeneous autoimmune disease, it is important to remember that no lupus patient looks like another. Each person has their own struggle and journey with the disease. It can mild, or severe enough to cause disability and even death.

I count myself lucky that I have mild to moderate lupus. As with all lupus patients I have periods of flares and remissions. Unfortunately, many lupus patients are not as lucky. In my work I see many lupus patients who are 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 systems. Lupus impacts almost every facet of a person's life, including relationships, employment, mobility, and finances.

I cannot tell you the number of lupus patients who have come to us, newly diagnosed, scared out of their mind. They immediately believe they are going to die and apply for disability to support them through the end of their lives. One patient in particular, who has become a good friend of mine, did exactly that. When she came to us, this is exactly what she thought would happen. But because she worked with us, she was able to see that there are many lupus patients who go to work and lead full and productive lives. She is now living well with lupus, going to her full-time job, and volunteering her time.

But her success story is not reality for all lupus patients. The economic impact of lupus can be devastating. The average annual total costs for people with lupus can be as high as \$50,000 and up to 55 percent of lupus patients reported a complete or partial loss of their income because they no longer are able to work full time due to complications of lupus. One in three have been temporarily disabled by the disease, one in four currently receive disability payments and receive their health care through a government-sponsored program, such as Medicare or Medicaid.

Our work is critical to helping lupus patients get a proper diagnosis, access the care that they need, be educated on living well with the disease, and continue to lead full and productive lives as best they can while living with chronic illness. We offer educational programs and services, patient assistance programs, lobby during advocacy initiatives, contribute to vital research, and provide a network of patient navigation support throughout the state. The list is honestly endless.

In recent years, the Ohio legislative body has recognized the importance of funding the Lupus Foundation of America, Greater Ohio Chapter's important programs and services. In the past four Ohio budget cycles, lupus has been funded in different capacities. And most recently, Senate Bill 234, designating May as Lupus Awareness Month, became effective on April 9th of this year. So, we know that you see the value in what we do.

Through our funding from the State of Ohio through the Ohio Department of Health we have made great strides. We continue to build off of the Lupus Needs Assessment which showed that more work needed to be done in order to reduce the personal and public burden of lupus in Ohio. Now we are better able to coordinate care services to better promote health outcomes of those living with lupus and reduce the public burden.

We greatly appreciate Governor DeWine for again including the Lupus Foundation of America, Greater Ohio Chapter in the Executive Budget for lupus education and awareness in the amount of \$500,000. Unfortunately, our funding was removed from the House Budget. **We respectfully urge the Ohio Senate to reflect the Executive Budget and restore the \$500,000 allocated to the Lupus Foundation of America, Greater Ohio Chapter, Inc. for funding the lupus education and awareness program.**

Thank you for your time.