

Good morning, Chairperson Carruthers, Ranking Member Liston, Representative Hoops, Representative McNally, and Representative Schmidt.

It is an honor to appear before you today at this important hearing. My name is Adrienne Fernandez. For the past 10 years, I have 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 network of chapters and regional offices are located in communities across the United States. The Foundation is devoted to solving the mystery of lupus.

I stand here before you, not only as an employee of the LFA but also as a patient. I found my way to the Lupus Foundation of America, Greater Ohio Chapter, and as many patients will tell you, they were literally a lifesaver – so much so that I decided to join the organization. Now I spend my days helping others who suffer and educating them on how to live a better life with lupus.

For those of you unfamiliar with the disease lupus, I will provide you with a brief overview. Lupus is a chronic autoimmune disease that can damage any part of the body from the skin and joints to major organs. In lupus, autoantibodies attack and destroy healthy tissue. Lupus can be mild or can be severe enough to cause death.

Allow me to give you some key facts:

- The cause of lupus remains **UNKNOWN** and there is **NO** cure.
- Lupus is among the leading causes of death in young women.
- Lupus is chronic, meaning if you have lupus, you will always have lupus.
- On average it takes 6 years for people with lupus to be diagnosed.
- It is estimated that 60,000 Ohioans and 1.5 million Americans have lupus.
- 9 out of 10 persons with lupus are women, though men and children can still get the disease.
- Lupus is two to three times more prevalent among minorities.
- 1 in 3 lupus patients has been temporarily disabled by the disease and 1 in 4 receive their healthcare through a government-sponsored program such as Medicare or Medicaid.
- \$50,000 is lost annually by each lupus patient in healthcare costs and lost productivity.
- Before 2021, only **ONE** medication has been developed specifically to treat lupus in the past 55 years. Now we have an additional three treatments which may not seem like much, but to us it is monumental.

In 2016, the state of Ohio, through the Ohio Department of Health, determined that a Lupus Needs Assessment was necessary. So, in response to this determination, funds were given to identify, collect, and analyze data that provided better insight into lupus and how to coordinate care services to promote better health outcomes of individuals living with lupus in Ohio.

Key findings of the *Assessment* revealed that much work needed to be done in order to support lupus patients and reduce the personal and public burden of the disease. The Lupus Foundation of America, Greater Ohio Chapter has been working diligently since the Lupus Needs Assessment was published in 2017 to ensure we are responding to and implementing the key recommendations revealed by the Assessment. Some highlighted accomplishments include:

- Over 100 partnerships were created with state healthcare agencies. This outreach created much-needed awareness and education for the populations most at risk.
- Over 460 healthcare professionals received the Lupus Education for Healthcare Professionals CME/CEU training. This prepared them to be on the lookout for lupus and to be better equipped to treat lupus patients.
- Over 2000 lupus patients attended statewide lupus summits, providing them with access to much-needed lupus patient education, support, and resources.

- We created a lupus toolkit for patients and caregivers which is active on the LupusGreaterOhio.org website and contains vast resources. This is one of our most utilized assets on the LFA, GOC website.
- We created a podcast and blog featuring patient experiences and the latest most up-to-date information regarding lupus.
- We created and produced a quarterly magazine which is shared 65,000 times per year.
- We created and implemented KNOW Lupus and Could You Have Lupus marketing campaigns utilizing social media, YouTube, SEO/SEM, Google Ad Words, Spectrum reach commercials, billboards, and public service announcements. The digital reach was over 5,000,000 and generated over 2200 lupus screening quiz responses.
- Implemented a minority-specific PSA campaign.
- We hosted a Lupus Disparities Education Summit. The reach was over 200 people.
- Implemented a statewide Patient Navigation program. We utilize 10 patient navigators across Ohio to reach the most vulnerable lupus patients and reduce barriers to care.
- We Provide transportation assistance, mental health assistance, and medical financial assistance to lupus patients.
- We utilize an outreach coordinator to connect lupus patients in minority communities with available resources and services.

As you can see, we've been working very hard to meet the needs of lupus patients across Ohio. The Ohio legislature can rest assured that we are excellent stewards of the state's funding and fervently dedicated to our mission.

We greatly appreciate Governor DeWine, the Ohio Department of Health, and the Ohio House of Representatives for including the Lupus Foundation of America, Greater Ohio Chapter in their budget for lupus education and awareness in the amount of \$420,000 (FY 2024 and FY 2025 combined).

Due to the pandemic and increases in food insecurity, we have noticed a marked increase in requests for food assistance from lupus patients across Ohio. In addition, we have been asked by multiple health agencies for further lupus continuing education programs for healthcare workers. We would like to address these issues by requesting a 19.04% increase to \$500,000 over the biennium. Thank you to representative Hoops for drafting language to reflect this change.

We believe that funding is critical to reducing the burden of lupus in the state of Ohio. I know that you have many requests for funding and we know that so many causes are important. Thank you for recognizing that there are 60,000 people in Ohio living with a chronic, painful, and potentially deadly illness for which there is no known cause and/or cure. Thank you for your time.