

Good morning, Chairman Dr. Huffman and members of the Ohio Senate Health Committee,

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. I stand here before you, not only as an employee of the LFA but also as a patient.

Let me take a moment to tell you about my lupus story. My journey with autoimmune disease began when I was five years old. I woke up one morning with a body-wide rash and swollen joints. As time went on, I developed a 105-degree spiking fever, a swollen liver, and a swollen spleen. I lost a significant amount of weight. I was fortunate to have a physician for a father as they allowed me to stay at home and not be admitted to the hospital. It is now believed that I had Systemic Onset Juvenile Idiopathic Arthritis, though, at that time, little was known about the disease. Over time, my illness went away, but my joint pain remained. Fast forward to my 23<sup>rd</sup> year of life. I was overjoyed to be living with my college friends and enjoying life as a newly graduated young professional. Unfortunately, this joy was overshadowed by an influx of joint pain, fevers, and a new onset rash. My father sent me to a rheumatologist friend who ended up determining that I had some type of autoimmune disease, though he could not say what. I was always told, "You may have lupus". As with most patients who eventually get diagnosed with lupus, new signs and symptoms began to appear. In addition to rashes, joint pain, and fatigue, I developed another autoimmune disease called Sjogren's. My bloodwork looked worse and soon thereafter I was diagnosed with lupus. In the past several years, my lungs have been impacted by multiple bouts of pleurisy and signs of pleural effusions. But I am lucky. I live with lupus, yes, but believe it or not, I am one of the fortunate ones. I am not permanently disabled by my disease. So far, my lupus does not impact my central nervous system. I have not been plagued by strokes, cardiovascular complications, or renal failure. I am fortunate to have been raised by a physician, have a husband who is a physician, a brother-in-law who is a physician, and work for a foundation dedicated to the disease that I have. I recognize the privilege that I have. But what happens to people who don't have family members or friends in healthcare?

They've been told they have a chronic disease they may not have ever heard of with no known cause or cure that can possibly kill them. To no fault of their own, the physician has 15-30 min to explain a disease that can impact virtually every body system and organ and review a host of lifestyle modifications and medications that may or may not work. Unfortunately, this is the reality for many of the estimated 60,000 Ohioans and 1.5 million Americans living with lupus today.

This is where the Lupus Foundation of America steps in. We offer education, support, literature, research, and advocacy. We are there as an additional resource for patients and help to make their journey with lupus better.

We have worked tirelessly to support lupus patients and recognize their needs through many projects. One such project was the Ohio Lupus Needs Assessment. In 2016, the state of Ohio, through the Ohio Department of Health, determined that a Lupus Needs Assessment was necessary to provide better insight into the personal and public burden of lupus. Key findings of the Assessment revealed that much work needed to be done. The Lupus Foundation of America, Greater Ohio Chapter has been

working diligently to address these findings since the Lupus Needs Assessment was published. 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.

We greatly appreciate Governor DeWine for including the Lupus Foundation of America, Greater Ohio Chapter in his budget for lupus education and awareness in the amount of \$420,000. 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.

We believe that funding is critical to reducing the burden of lupus in the state of Ohio. We know that you have many requests for funding, and all are important. So, I genuinely thank you for your time and welcome any questions you may have.