

Chairman Hackett, Vice Chair Huffman, Ranking Minority Member Thomas and distinguished Members of the Committee, it is an honor to appear before you today at this important hearing.

My name is Adrienne Fernandez. For the past 6 ½ years, I have worked for Lupus Foundation of America, Greater Ohio Chapter. The Lupus Foundation of America is a national health organization devoted to solving the mystery of lupus, one of the world's cruellest, most unpredictable and devastating diseases, while giving caring support to those who suffer from its brutal impact. Our mission is to improve the quality of life for all people affected by lupus through programs of research, education, and advocacy.

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.

Let me 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.
- Only **ONE** medication has been developed specifically to treat lupus in the past 55 years.
- 1 in 3 lupus patients have been temporarily disabled by the disease and 1 in 4 receive their healthcare through a government sponsored program such as Medicare or Medicaid.

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 educate them on how to live a better life with lupus.

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 Minority Set-Aside Contractor, RAMA Consulting who partnered with subject matter experts, the Lupus Foundation of America, Greater Ohio Chapter to identify, collect, and analyze data that provided better insight into the personal and public burden of lupus in Ohio and how to coordinate care services to promote better health outcomes of individuals living with lupus.

Key findings of the *Assessment* revealed that 1) the complexity of lupus makes it extremely difficult to diagnose and treat; 2) lupus subject-matter experts are needed to promote lupus education curriculums to “early responders”; 3) there is a lack of awareness in communities regarding lupus; and 4) existing data systems need to be coordinated to develop a better epidemiological profile of lupus.

In response to the Lupus Needs Assessment, five specific recommendations were formed. In conjunction with RAMA Consulting, the Lupus Foundation of America, Greater Ohio Chapter was able to meet the criteria that ODH set forth and developed a *“Statewide Lupus Education Initiative for Health Professionals”* CME/CEU program. The program was designed and implemented to target a broader range of “early responders” and support services and to promote lupus education curriculums to these early responders. Finally, additional funding was provided with the overall purpose of providing outreach to patients diagnosed with lupus.

- Over 50 partnerships with state agencies and healthcare agencies were established.
- Over 460 healthcare professionals received the Lupus Education for Healthcare Professionals CME/CEU training.
- Over 400 lupus patients attended statewide lupus summits, providing them with access to much-needed lupus patient education, support and resources.
- A lupus toolkit was distributed to over 5000 healthcare providers across the state.

Even after these accomplishments, there are still four recommendations made by the state of Ohio in the Lupus Needs Assessment that need to be met in order to reduce the personal and public burden of lupus. The Lupus Foundation of America, Greater Ohio Chapter wants to continue working towards completion of the Lupus Needs Assessment by focusing on three of these recommendations in order to meet the needs of lupus patients across Ohio.

We thank the House in recommending funding for Lupus Education, Awareness, and Prevention. (\$93,120 each year). However, we are asking the Senate to increase the funding that was recommended by the House so that we can complete the recommendations as made by the state in the Lupus Needs Assessment. On behalf of the 60,000 Ohioans living with lupus, we request that \$500,000 annually, be included in the Ohio Department of Health 2020-2021 budget, specifically designated to the Lupus Foundation of America, Greater Ohio Chapter, Inc. to fulfill the recommendations made by the state of Ohio in the 2016 Lupus Needs Assessment for the purpose of Lupus Education, Awareness, and Prevention.

The Lupus Foundation of America, Greater Ohio Chapter appreciates the Committee’s interest in considering funding for Lupus Education, Awareness and Prevention. 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. I hope when you consider our request, you will remember that there are 60,000 people in your own state living with a chronic, painful and potentially deadly illness for which there is no known cause and/or cure. Thank you for your time.