

My name is Suzanne Tierney. I am currently the CEO of the Lupus Foundation of America, Greater Ohio Chapter. I believe I stood here at the statehouse to give testimony about lupus ten years ago. It was then that we presented a Lupus Education, Awareness, and Prevention (LEAP) Bill along with the help of then Representative Sandra Williams. When it was my turn to speak, most of the committee got up and left. As you can imagine I was quite offended that lupus meant so little to those that make some of the decisions here in Ohio.

I do want to thank you all for your time and I can imagine the challenges that are presented to you daily. Today I only pray my voice is heard because I do consider it a privilege to be the voice of thousands of people in Ohio impacted by lupus.

We have just celebrated my 30th year with the LFA. We are a grassroots organization that has been in existence for over 40 years. We were created by lupus patients and their families so that there would be a movement to find the cause, cure, better treatments for lupus and to create much needed awareness.

I can only be as honest and sincere as possible. I feel too often my message is not heard or received because people don't want to take the time to understand lupus.

Lupus is a serious disease that impacts about 60,000 Ohioans. Mostly young women in the prime of their lives. It affects women of color 2-3 times more; it affects men worse and young children when diagnosed usually have organ involvement. It is the tenth major cause of death in this nation, excluding accidents. We do not know what causes lupus and we have no cure. It impacts everyone differently, making it difficult to diagnose and treat.

We borrow medications that are approved for other diseases and have had only one drug approved by the FDA in over 55 years. Which, by the way, is not a drug for everyone. The cost is prohibitive, and it is given by infusion. To educate you about lupus would take hours, I have included in your packages much more information about the cruel and mysterious disease we call lupus for your review. Please acquaint yourself with the materials.

The Lupus Foundation of America leads the way in the lupus movement and is the leading authoritative source for information about lupus in this county. We have made great strides on the national level.

I have just returned from Washington where, together with over 400 lupus advocates, we made the following asks of Congress.

1. \$10 million dollars for the Lupus Research Program at the Department of Defense. Which last year was awarded for the first time \$5 million dollars specifically for lupus.

Right here at Children's Hospital in Cincinnati they were able to receive a research grant for children.

2. \$8 million for the Centers for Disease Control and Prevention (CDC) National Lupus Patient Registry
3. \$2 million for the Office on Minority Health, National Lupus Training, Outreach & Clinical Trial Program
4. \$41.6 billion for the National Institutes of Health, an increase of \$2.5 billion for the largest source of lupus funding which provide \$115 million for lupus research last year alone.

We will remain confident that are asks are heard there. The fruition of these will ultimately have an impact on Ohioans. But finding the causes, treatment and cure for lupus will take time.

Here in Ohio we need to act now. There is more awareness today than ever, in the sense that the general public and medical community have heard of lupus. The enormous problem is that many do not understand the disease. This is a huge issue that needs our immediate attention.

In the last fiscal year, Senator Sandra Williams, who knows firsthand about lupus, was able to make an ask in the budget for over \$500,000. Her goal was to raise much needed funds for education, support and to help lupus patients navigate their journey and empower them to learn better self-management so they have a better quality of life.

The funds went to the ODH, which awarded a contract to a minority set aside contractor. The Lupus Foundation of America, Greater Ohio Chapter, as subject matter experts, worked with the contractor for two years. The first year we created focus groups across Ohio, we assembled a committee of physicians from across the state to identify issues and concerns. From this came the first ever "Ohio Lupus Needs Assessment". This assessment is a roadmap to address critical issues of those here in Ohio regarding lupus.

The assessment is enclosed for your review. We recognize that some of the directives in the assessment are long reaching goals and much funding is needed. We are striving to reach the directives that are more achievable.

We were able to create an educational program for clinicians about lupus. Because of this project we were able to train over 400 clinicians and offered CEU's and CME's that speak to lupus. A minority component was created, and we created partnerships with over 50 other groups across the state. This project also allowed us to create a "Tool Kit" for physicians and patients. It is currently housed on our chapter's website. This is a resource for both the

clinician and the patients. We also held lupus education summits across Ohio and reached another 400 lupus patients and their families.

Today we have hundreds of people that are better educated and prepared to travel the lupus journey because of the funding we received previously. The project presented the latest and most accurate information there is about lupus. Knowledge is power whether you are the clinician, the patient or the family.

How do I know this? I have lupus too. I was misdiagnosed for 19 years. It is a miracle that I survived this lonely, misunderstood and miserable disease. I am a stroke survivor and currently not only have lupus but multiple other autoimmune issues to deal with. I am currently on 23 pills a day. Yet to you...I do not look sick. This phrase resonates in my head over and over. I cannot tell you how frustrating my life is. I have a passion to help those impacted by lupus because I can relate to the misery that one encounters on this journey. Just this week alone I have four doctor appointments, one x-ray, one ultrasound and one brain scan. I have been to the drug store four different times. Yet, I do not look sick. The medical community is a jungle. I cannot imagine what an everyday person goes through trying to navigate through it. The multitudes of physicians and appointments, the landscape of the parking garages itself it a nightmare. Transportation, drug stores, new meds, old meds, the cost of treatment. How is anyone expected to hold a job and manage a family let alone your own health needs? By the way, I see the best of the best and I am still not confident that they even know what they are doing. I feel like I am ranting but the reality is this journey is complex and horrifying.

What can we do? We need to stop the mystery. We need to create a lupus community that works in sync with each other. We are on the road to understanding this disease but until then we need awareness about lupus. Without awareness and knowledge, the cruelty will continue. To have no lupus we must KNOW lupus.

Last Saturday I was in Cincinnati doing an educational summit with over 100 registrants. I have enclosed notes from them addressing some of their issues for your review. I think it is important to see the impact the disease has in the patients' own words.

I am asking that you support HB 166 GRF 440481 to help us do capacity building in the areas of education, awareness and patient and support. We have a springboard with the Ohio Lupus Needs Assessment, and we need to continue the momentum. We will not be able to do it without your support.

As for me I don't look sick, but I am, and God is in my wheelhouse. God bless you and thank you for your time and consideration. Happy to speak with any of you on any concerns.

