

Members of the House Finance Health and Human Services Subcommittee, it is my pleasure and honor to stand before you today.

My name is Suzanne Tierney. I am the CEO of the 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 cruelest, 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. The cause(s) of lupus remains unknown and there is no cure. It is a leading cause of death in women and on average takes 6 years to diagnose.

Each person with lupus has a different story. Since lupus can impact each one differently it is exceedingly difficult to manage and treat.

I stand here before you, not only as a CEO, but also as a patient. My journey with lupus began when I was 9 years old. I was misdiagnosed for 19 years and spent most of my life on the sidelines, watching my healthy twin live a full and active life. Finally, after the birth of my first child, I was diagnosed with lupus. Unfortunately, I was told to get my affairs in order, that I only had few years to live. That was 43 years ago. Through the help of many physicians, a multitude of medications, a strong support network and the Lupus Foundation of America, I am alive and living life to the best of my ability. That's not to say there haven't been setbacks. I have a multitude of autoimmune diseases (this is typical of lupus; you get other related diseases). I take 23 pills per day. I am a stroke survivor and battle chronic pain daily. The peaks and valleys will always be part of my life with lupus.

During my journey it was a lonely, misunderstood and miserable life. Today it does not have to be. I have spent decades trying to make change in the world of lupus and as the CEO of the Lupus Foundation of America, Greater Ohio Chapter it has been my springboard and that is to help those who suffer in silence and to be their champion in the fight against lupus.

It has been a privilege to be the voice of the over 60,000 Ohioans that we suspect are impacted by lupus. I have sat at hundreds of bedsides and have been at way too many funerals of mostly young women impacted by lupus.

It has only been recently that we have made great strides in the fight against lupus here in Ohio. In 2016 we came to you and asked the state of Ohio to fund the first ever statewide lupus needs assessment. This has been a guiding document in making momentous change together.

The Lupus Foundation of America, Greater Ohio Chapter appreciates the committee's interest in considering funding for Lupus Education, Awareness and Prevention. Yes, I come back to you again for your support, we are asking the Senate to include 500,000 biennially to the Lupus Foundation of America, Greater Ohio Chapter for Lupus Education, Awareness, and Prevention and to continue doing the great work that the Ohio Lupus Needs Assessment recommended.

My colleague will share with you the great accomplishments of your funding and I can assure you that these dollars were well spent, and the state can be very proud of the accomplishments. We cannot do this work with out your support.

Thank you for your time and I welcome any questions you may have.