Chairman Dolan, Vice Chair Burke, Ranking Member Sykes and distinguished Members of the Senate Finance Committee, it is an honor to appear before you today at this important hearing.

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.

The Lupus Foundation of America, Greater Ohio Chapter has been actively pursuing funding in the state budget for the purpose of completing the recommendations of the Lupus Needs Assessment which was conducted by the Ohio Department of Health in 2016 for the purpose of determining the personal and public burden of lupus in the state of Ohio. The Lupus Needs Assessment was a great accomplishment. It determined that there were critical unmet needs of Ohio lupus patients. The Lupus Foundation of America, Greater Ohio Chapter worked with RAMA Consulting to complete one of the five Lupus Needs Assessment recommendations. We were able to educate over 460 healthcare providers across Ohio, educate 400 lupus patients, form 50 community partnerships and distribute a lupus toolkit 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.

The House has recommended funding in a much smaller increment than what is necessary for us to complete the recommendations of the Assessment as determined by the state. While we are grateful to the House, it is truly our goal to complete the recommendations made by the Lupus Needs Assessment. Therefore, on behalf of the 60,000 Ohioans living with lupus, we request that $750,000 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.

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.

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 five years to live. That was 30 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. 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. But I have a true purpose as CEO of the Lupus Foundation of America, Greater Ohio Chapter and that is to help those who suffer in silence and to be their champion in the fight against lupus.

The Lupus Foundation of America, Greater Ohio Chapter appreciates the committee’s interest in considering funding for Lupus Education, Awareness and Prevention. Again, we are asking the Senate to include $750,000 annually to the Lupus Foundation of America, Greater Ohio Chapter for Lupus Education, Awareness, and Prevention and to complete the Ohio Lupus Needs Assessment recommendations.

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