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 funding has ended from ODH. We are seeking funding to continue the project recommendations. It was not the intent of the LFA to take away funds from the Lupus Projects funded by the Ohio Commission on Minority Health. It appears that there is some confusion and that the funding that the Commission has received for the past 20 years were being directed to the LFA. We are asking that you reinstate their funding and consider funding to the Lupus Foundation of America, Greater Ohio Chapter to continue the work that was started with ODH.

The House did recommend 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. I am here to clarify that these are two different projects. Both vital to the 60,000 Ohioans living with lupus, we request that a larger amount annually, to 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. Again, we are asking the Senate to include at least $500,000 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. Please do not leave us without any funding. There is much work that needs to be done and honestly it won’t get down without your help. Most people do not know lupus and there fore to raise the funds needed to are work is lagging behind because of it.

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