

Members of the Senate Finance Committee,

My name is Suzanne Tierney, and it's my pleasure to submit testimony today as President & CEO of the **Lupus Foundation of America, Greater Ohio**

Chapter, one of only five LFA chapters across the US. The Lupus Foundation of America is a national health organization dedicated to solving the mystery of lupus—one of the world's cruelest, most unpredictable, and devastating diseases—while providing crucial support to those affected. Our Ohio chapter strives to improve health outcomes through **early detection and treatment**, offering education, support, patient navigation, resources, and self-management teaching. Awareness, advocacy, and research are key to better treatments and a cure.

My Personal Battle with Lupus

Lupus is a leading cause of death for young women, and its varied impact makes it incredibly difficult to manage. Someone you know has lupus, and today, that person is me. My journey began at age nine, followed by 19 years of misdiagnosis. I was finally diagnosed after my first child was born, and tragically told I only had a few years to live. That was over 45 years ago. I now take 23 pills daily, am a stroke survivor, and battle chronic pain. My life with lupus has had its peaks and valleys, but with the help of physicians, medications, a strong support network, and the Lupus Foundation of America, I am here, living life to the best of my ability.

My early journey was lonely and misunderstood. As CEO, I've spent decades working to change that, championing those who suffer in silence. It's been a privilege to be the voice for the over **60,000 Ohioans we suspect are impacted by lupus**. I've witnessed firsthand the devastation, attending too many funerals of young women lost to this disease. Just weeks ago, I comforted a distraught mother who lost her 18-year-old daughter. These moments reinforce the critical importance of our mission.

Progress and the Current Challenge

We have made significant strides recently. In 2016, you funded Ohio's **first-ever statewide lupus needs assessment** - the only one of its kind in the nation. This document guides our efforts in understanding and addressing lupus's burden. You should also be proud of the recently passed **Senate Bill 234, designating May as Lupus Awareness Month**. Our programs deliver measurable success in early diagnosis and self-management, which are essential for those living with lupus.

However, we face a critical challenge. While the Governor's Executive Budget included our crucial funding for lupus education and awareness, I was devastated to learn it was **cut from the House Budget**. This comes at an extremely fragile time: our donations haven't rebounded to pre-pandemic levels, corporate and pharmaceutical funding is down, and our national organization has seen congressionally directed funding cuts to vital research and public health initiatives. This confluence of factors creates an incredibly volatile time for us.

Our Plea

Being included in the Ohio budget is not just helpful; it's **crucial to the sustainability of our patient programs and services**. Without your support, we cannot continue our work. Lupus patients in Ohio rely on our programs for disease management, and they are already worried about potential Medicaid cuts. Without these funds, they will suffer and have nowhere else to turn.

I respectfully ask you to **reinstate the \$500,000 in funding** that the Governor included in his Executive Budget for lupus education and awareness, so we may continue our critical work.

Thank you for your time and consideration.