Members of the Senate Medicaid Committee, it is my pleasure and honor to stand before you today.

My name is Suzanne Tierney. I am the President & 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 most 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.

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, and that I only had a few years to live. That was over 45 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. As the CEO of the Lupus Foundation of America, Greater Ohio Chapter, I have spent decades trying to make change in the world of lupus. It has been my mission 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 here in Ohio. I have sat at hundreds of bedsides and have been to way too many funerals of mostly young women impacted by lupus. Just a few weeks ago I spent many hours with a distraught mother who lost her 18-year-old daughter to the disease. It is in these times that I realize how important our mission truly is.

It has only been recently that we have made great strides in the fight against lupus. In 2016 we came to you and asked the state of Ohio to fund the first-ever statewide lupus needs assessment. You should be proud because to this day it remains the only Lupus Needs Assessment conducted by any state in the nation. It helped us determine the personal and public burden of lupus here in Ohio and has been used as our guiding document. You should also be proud of the recently passed Senate Bill 234, designating May as Lupus Awareness Month.

We are grateful to have been included in the Ohio budget in recent funding cycles for lupus education and awareness. This being said, I am here to tell you that while we were included in the Governor's Executive Budget, our funding was cut from the House Budget. This comes at an extremely fragile time for our Chapter. Our donations have not yet reached pre-pandemic levels due to the economy. In addition, corporate foundations are down, and our pharmaceutical funders have pulled back. Our National organization has had congressionally directed funding cuts that negatively impact vital lupus research, drug development, and public health initiatives. All of these factors combined make for an extremely volatile time in our world. We hope you understand that being included in the Ohio budget is crucial to the sustainability of our patient programs and services. Without your support, we cannot continue the good work that we do. As Adrienne just shared with you, many lupus patients rely on Medicare/Medicaid and are on disability. They depend on our many programs and services to help manage their disease. They are already worried about potential Medicaid cuts. Without these funds, lupus patients in Ohio will suffer.

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

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