Help Us Solve
The Cruel Mystery
LUPUS™
FOUNDATION OF AMERICA
GREATER OHIO CHAPTER

Dear Members of the Senate Health Committee,

My name is Suzanne Tierney. I am the President & CEO of the Lupus Foundation of America, Greater Ohio Chapter. I have been with the organization for over thirty years and have also served in several leadership positions with the National office in Washington D.C.

I would like to thank you for taking the time to read my testimony. In previous years, I have traveled to the statehouse to meet with you in person. However, as a lupus patient, I am taking my doctor's advice and staying as close to home as possible during the pandemic.

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.

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 severe enough to cause death. Please allow me to share some key facts about lupus:

- ✓ Despite years of research, the cause remains **UNKNOWN** and there is **NO CURE**.
- ✓ Lupus is chronic, meaning once you have lupus, you will always have lupus.
- ✓ On average, it takes **SIX** years for people with lupus to be diagnosed.
- ✓ One in three lupus patients have been temporarily disabled by the disease and one in four receive their healthcare through a government sponsored program such as Medicare or Medicaid.
- ✓ Lupus is two to three times more prevalent in women of color.
- ✓ Nine out of ten people with lupus are women.

These statistics are startling. I often wonder how, in today's age full of medical advancements and cutting-edge research, we can possibly have no cure or true understanding as to what causes lupus.

I write to you not only as a CEO, but also as a patient. My journey with lupus began when I was nine years old. I was misdiagnosed for nearly 20 years and spent most of my life on the sidelines watching my perfectly healthy identical twin live a full and active life. Finally, after years of frustration I was diagnosed with lupus. At that time, lupus did not have many treatment options and I was told to "get my affairs in order." I am happy to report that thirty years later, I have beat those odds. Through the help of many physicians, a multitude of medications, a strong support system including the Lupus Foundation of America, my family, and the grace of God, I am here today.

I do struggle. I am a stroke survivor. I manage chronic pain and have multiple autoimmune diseases. I take over twenty-five pills per day and many times it is hard to get out of bed. The peaks and valleys will always be part of my life with lupus, but nevertheless I persevere. I have found a true purpose as the leader of the Ohio Chapter of the Lupus Foundation of America. There are an estimated 60,000 Ohioans who have lupus, and I am here to be their champion in the fight against the disease.

In 2016, the state of Ohio, through the Ohio Department of Health, determined that a Lupus Needs Assessment was necessary. So, in response to this determination, funds were given to Minority Set-Aside Contractor, RAMA Consulting who partnered with subject matter experts, the Lupus Foundation of America, Greater Ohio Chapter to identify, collect, and analyze data that provided better insight into the personal and public burden of lupus in Ohio and how to coordinate care services to promote better health outcomes of individuals living with lupus.

Key findings of the *Assessment* revealed that 1) the complexity of lupus makes it extremely difficult to diagnose and treat; 2) lupus subject-matter experts are needed to promote lupus education curriculums to "early responders"; 3) there is a lack of awareness in communities regarding lupus; and 4) existing data systems need to be coordinated to develop a better epidemiological profile of lupus.

For the past several years, due to support from the state of Ohio, we have been able to make a concentrated effort to close the gaps discovered by the Lupus Needs Assessment. We have made great progress, but there is much work to be done in order to secure a better future for lupus patients. As an addendum to this letter, I've included the measurable progress we've made with the last round of funding. I can assure you, as CEO of the Foundation, taxpayer dollars did not go to waste.

The Lupus Foundation of America, Greater Ohio Chapter is tremendously grateful to be included in both the Governor's Executive Budget and House Bill 110 as approved by the House. On behalf of the 60,000 Ohioans living with lupus, we respectfully request that the Senate keep the recommendation made by the House in HB 110 for $210,000 annually to be distributed to the Lupus Foundation of America, Greater Ohio Chapter for lupus awareness.

In closing, I would like to take a moment to tell you how important the state funding has been during the COVID-19 pandemic. Lupus patients are considered immunocompromised, so during the pandemic they faced not only the unknown, but also fear and isolation. While all fundraising had ceased, demand for services at the Foundation increased at a rapid rate, especially in vulnerable communities. The staff quickly revamped programs and services to meet the needs of lupus patients. The impact of the pandemic is still with us today. We are working harder than ever, with less resources. I think it is important for you to know how much your support and funding has meant to lupus patients across Ohio, now and in the future. I pray you will continue this funding; it is critical to the health and wellbeing of lupus patients across Ohio.

I can be reached at suzanne@lupusgreaterohio.org or 1 (888) NO-LUPUS if you have any questions or require further information. Thank you for your time.

Sincerely,

Suzanne Tierney

Suzanne Tierney
President & CEO, Lupus Foundation of America, Greater Ohio Chapter

THE MEASURABLE ACCOMPLISHMENTS

The Lupus Foundation of America, Greater Ohio Chapter has accomplished the following (and more) with funding from the State of Ohio through the Ohio Department of Health:

- ✓ Increased lupus awareness with a statewide KNOW Lupus Campaign which utilized digital technology and marketing. Display advertisements reached **125,000 impressions** per month.
- ✓ Released a PSA campaign, targeting those at risk of developing lupus (specifically people of color), resulting in a **10% increase** in inbound inquiry calls and email requests for information as well as a **5% increase** in program attendance.
- ✓ Implemented a social media campaign with weekly “hot news” topics related to lupus and reached over **40,000 people**.
- ✓ Distributed updated lupus information to over **300 physicians’ offices** across Ohio.
- ✓ Created digital ***Living with Lupus*** magazine with distribution of 4x per year to over **15,000 constituents** across Ohio.
- ✓ Hosted three **digital lupus education summits** with **12 presenting physicians/lupus experts** with a combined audience of over **520 attendees**.
- ✓ Hosted **5 in-person lupus education summits** (three in less populated areas) across the state of Ohio with **14 physicians/lupus experts** with a combined audience of **100 attendees**.
- ✓ Established over **twenty community partnerships** with organizations to help create lupus awareness.
- ✓ Implemented two digital and two in person (Cincinnati & Cleveland) “KNOW LUPUS ZONE” meetings.
- ✓ Trained **three minority organizations** on lupus to recognize the symptoms and spread awareness.
- ✓ Hired and trained **20 patient navigators** across the state to meet the needs of lupus patients across Ohio.
- ✓ Implemented diversity and disparities training to community leaders across the state of Ohio.
- ✓ Implemented a “Be-Fierce” **minority-specific digital marketing campaign** and targeted 30 minority-specific social media sites with a **digital reach of 10,000+**.
- ✓ Created **new website with an updated toolkit** in order to meet the needs of Ohio lupus constituents with improved content, usability, and updated and new resources.
- ✓ Created an innovative **lupus podcast** with **fifty regular subscribers**, called “My Lupus Living Room,” a space where candid conversations about topics related to lupus that often get overlooked are discussed.
- ✓ Reached over **100** additional constituents through the creation of a **patient-driven blog** called “The Lupus Night Light.”
- ✓ Conducted over **1000 telephonic wellness checks** on Ohio’s most vulnerable lupus patients during the COVID-19 pandemic.