

Committee,

Since 1977, The Foundation of America, Greater Ohio Chapter has been dedicated to improving the quality of life for all people affected by lupus through programs of research, education, support, and advocacy. To accomplish all of this, it is vital to create awareness about lupus.

Lupus is an autoimmune disease with no known cure and causes unpredictable and chronic flare-ups that include fatigue, pain, organ involvement, rash, fever and so much more. There are four different categories of lupus.

1. SLE is the most common and is the most serious. It can affect many parts of the body, including blood cells and organs, such as the brain, heart, kidneys, lungs and skin with symptoms ranging from mild to severe. Many have Lupus Nephritis, which involves kidneys and can result in kidney failure and transplants.
2. Discoid or cutaneous lupus erythematosus is specific to the skin and is often exacerbated by the sun or UV lighting. Often it is followed by SLE. It can be a brutal disease impacting the skin and hair. People of color can lose pigmentation in the skin.
3. Drug-related erythematosus is caused by the consumption of pharmaceutical products like blood pressure and thyroid medications, antibiotic and antifungals, and many other medications. These symptoms typically will go away once the drug is stopped.
4. Neonatal lupus is a rare disease that can occur in newborn babies of women with SLE. At birth the babies have skin rash, liver and low blood count issues. These symptoms will decrease after time.

Here in Ohio, we suspect there are over 60,000 people with lupus. 90% of them are young women between the ages of 15-45 and a disproportionate number are African America. Men do get lupus, but sadly, they do appear to get it much worse.

This chapter is a small grass roots organization that has led the way to build a lupus community and is a part of a National Organization that is the leading source for the latest and most accurate information there is about lupus. Ohio is one of four other states in the Nation that has a chapter. I have been to the State Capital and our Nations Capital several times to be an advocate for lupus and have shared with them what lupus is and what is needed to help in our fight for a better tomorrow. As a result of these efforts in 2016, we worked collaboratively with ODH in creating the , the Statewide Lupus Needs Assessment for the state of Ohio, the first ever done for a state in our Nation. I have sent it along for your review. It is a roadmap that we use to meet the needs of those impacted by lupus here in Ohio. We are hopeful to update it next year.

Most importantly the assessment speaks about the need for more awareness. Although we have made great strides, we still struggle with this. Nearly eight years later we know that the general public has now heard of lupus and knows someone who has it. The struggle is: **they do not know what it is**. Everyone knows what heart disease, cancer and many others, but the world of lupus remains largely misunderstood. This creates problems on many fronts including public perception,

clinicians understanding, first responders understanding, potential donors and supports and especially those who are not yet diagnosed. **For there to be no lupus, we must first know it. That also includes research.**

Our website hosts a quiz “Could you have Lupus”? It receives over 3,000 views a month. It leads to the fact that people do not know what it is, and much work needs to be done.

The Lupus Foundation of America recognizes the Month of May as Lupus Awareness Month. We do focus on awareness campaigns on the radio, billboards, TV and much more. Each May we ask our constituents to help us promote this cruel disease by going to their local cities to seek proclamations. We do get dozens each year.

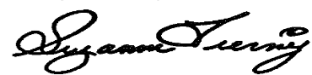
Today I am here to request your support of HB538. Why do we need awareness, what does it mean and the impact it could have. As a small organization we keep trying to gain traction in the war against lupus and we have made strides. But we need help.

One of the most important pillars of our mission is to reduce the time it takes to receive a diagnosis and treatment by raising awareness of the disease. The average diagnosis is almost 6-8 years. We feel by making people aware of the symptoms, it can help getting an earlier diagnosis to treat the disease before it becomes unmanageable. Creating more awareness in the medical field to be on the lookout is vital. Quicker diagnosis is key to living better with lupus.

Finding support for programs and resources from donors’ dollars is vital to our existence yet we lose this battle because the public does not understand it. It is very difficult to obtain corporate or philanthropic donors because they do not know lupus. What about the patient? Many do not speak or share their story because their circle does not know what it is. The patients themselves need education on the awareness of the disease. We need more research. The more people that know about it will help bring dollars and resources to help fund the cause and hopefully someday eradicate it.

I am asking as a voice for all the lupus patients here in Ohio and as a lupus warrior myself, please offer your support in passing HB 538. Designating May as Lupus Awareness Month in Ohio will help tremendously in spreading awareness about this cruel and debilitating disease. Please consider passing it. We need your support. We cannot do this alone. You too might know someone who has lupus. After all, in the word lupus there is only us. It will take all of us to make a better tomorrow for those impacted by lupus. I want to offer my gratitude to all that have taken their precious time to be a proponent today.

Respectfully,



Lupus Patient First

Suzanne Tierney, CEO and President

Lupus Foundation of America, Greater Ohio Chapter