

Rita Piccin, BS, ND, RN, Lead Patient Navigator/Outreach Coordinator, Lupus Foundation of America, Greater Ohio Chapter

As the lead patient navigator at the Greater Ohio Chapter, I am in contact with many lupus patients and their caregivers. I hear about the struggles and the suffering lupus patients endure every single day. I strongly urge you to pass HB 538, designating May as Lupus Awareness Month. This is why this bill is so important:^{1,2}

- Lupus is a chronic, long lasting autoimmune disease that impacts more than 60,000 people in Ohio and their families. 90% of lupus patients are women, and it often is diagnosed between the ages of 15-44, and tends to be more prevalent and more severe in minority populations. However, anyone can develop lupus at any time, including children, men, and the elderly.
- In lupus, the immune system is unbalanced and cannot tell the difference between healthy cells and tissues and foreign invaders to the body. This means the body attacks itself. Unfortunately, there is no known cure for lupus. It is a lifelong disease and does not go away.
- Lupus can affect so many different parts of the body, and it can cause a lot of different symptoms. The most common signs and symptoms include extreme fatigue or fatigue that will not go away regardless of how much rest a person gets. Pain or swelling in the joints which is often brought on regardless of one's level of activity. Sixty five percent of people with lupus list chronic pain as the most difficult aspect of lupus.
- Other symptoms include headaches, fever with no known cause, hair loss, swelling, pain in the chest with deep breathing, butterfly rash across the cheeks and nose, sensitivity to UV rays or photosensitivity, abnormal blood clotting and mouth or nose ulcers. It can damage any organ system of the body, including musculoskeletal system, skin, kidneys, immune system, brain and nervous system, heart, lungs, gastrointestinal system, and reproductive system.
- Lupus symptoms may come and go — and they can change over time. It is also heterogenous or different for each person and often presents symptoms that are similar to other diseases, which make it difficult to diagnose. As a result, the average time to receive a diagnosis and treatment is 6 years, which is way too long to endure needless suffering and debilitating tissue and organ system damage.

The Foundation of America, Greater Ohio Chapter is dedicated to improving the quality of life for all people affected by lupus through programs of research, education, support, and advocacy.³ 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. Passing HB 538, designating May as Lupus Awareness Month in Ohio, will help tremendously in spreading awareness about this cruel and debilitating disease and to reduce the average time to diagnosis and treatment. Thank you for your consideration.

¹<https://lupusgreaterohio.org/understanding-lupus/what-is-lupus/>

²<https://www.lupus.org/resources/lupus-facts-and-statistics>

³<https://lupusgreaterohio.org/about-us/#abtourmission>