



**Before the House Public Health Policy Committee
House Bill 538 – Designate Lupus Awareness Month
Sponsor Testimony by Representative Richard D. Brown
June 18, 2024**

Chair Mathews, Vice Chair Stewart, Ranking Member Liston, and members of the Public Health Policy Committee, thank you for allowing me the opportunity to testify in support of HB 538.

According to the Lupus Foundation of America, there are roughly 1.5 million people in the United States who are living with lupus. This is a chronic, long-term autoimmune disease that can cause pain and inflammation in any part of the body. In lupus, the immune system essentially attacks healthy tissues and organs. Lupus can affect many parts of the body including skin, joints, kidneys, blood cells, brain, heart, and lungs. There is no known cure at this time for lupus. Symptoms can come on slowly or quickly. Things can get better for a while then flare and get worse. Lupus can range from mild to life threatening, depending in large part on which parts of the body are being attacked by the immune system.

Systemic lupus erythematosus (SLE) is the most common form of lupus, however, there are several other variants. These include cutaneous lupus which is limited to the skin, drug-induced lupus which is a lupus-like disease caused by certain prescription drugs, and neonatal lupus which is a rare condition that affects infants of women who have lupus. While SLE is the most common form of lupus, it can lead to additional health issues like lupus nephritis which is a kidney disease caused by lupus that affects the parts of the kidneys that filter waste, causing inflammation, swelling, irritation, and in the worst cases, kidney failure.

While anyone can develop lupus, there are certain groups of people who are at higher risk. These include women ages 15 to 44, African Americans, and people who have a family member with lupus or another autoimmune disease. Currently, 9 out of 10 people with lupus are women. When looking at those affected by lupus, 65% of people say that chronic pain is the most difficult part of having lupus, 76% say fatigue caused by lupus has forced them to cut back on social activities, and 89% of people with lupus say they can no longer work full-time due to complications. People with lupus frequently experience muscle pain, joint stiffness, anemia, fatigue, fever, malaise, mouth ulcers, skin rashes, hair loss, anxiety, headaches, Raynaud's Syndrome, swelling of the joints, water retention, and sensitivity to light. While no one knows what causes lupus, it has been determined that it can run in families, and experts think it may develop in response to certain hormones like estrogen, or environmental triggers.

Treatment for SLE depends on the symptoms. Medicines include pain relievers, medicines used to treat malaria, steroids, biologics, and medicines that lower immune system responses.

Since lupus is considered an "invisible illness," due to its symptoms that can be difficult for others to recognize, and for doctors to diagnose, it's necessary that we work to bring recognition to the disease that affects thousands of Ohioans.

My interest in Lupus and desire to bring recognition to this disease is personal, as my wife suffers from Lupus. For many years now she has battled this insidious disease, which affects her life on a daily basis. Some days she can hardly walk, while other days she has no joint stiffness. She never knows what tomorrow will bring. She suffers from hair loss, overall muscle pain, joint stiffness, and sometimes debilitating fatigue. She takes many daily medications to try to combat these symptoms. Sometimes they bring relief, many times they do not. Despite these problems she soldiers on, working full-time, trying to remain as active as possible, and staring this disease in the face, as is her nature. Others who are not blessed with her intestinal fortitude would likely not handle these issues as successfully. Her condition could worsen and likely will as time passes.

HB 538, if passed, will designate May as Lupus Awareness Month in Ohio, bringing needed recognition and awareness to programs dedicated to improving the quality of life for all people affected by lupus. This legislation also directs attention to the Ohio Department of Health's ongoing Lupus Education and Awareness Program, established in 2012. For those seeking to support those affected by lupus and to raise awareness, the Lupus Foundation of America Greater Ohio Chapter will be hosting a "Walk to End Lupus Now" in Columbus on August 17th at COSI and in Cleveland on September 14th at Flats East Bank.

Please join me and my joint sponsor Rep. Upchurch in saying 'yes' on HB 538. Chair Mathews, Vice Chair Stewart, Ranking Member Liston, and members of the Public Health Policy Committee, thank you for allowing me the opportunity to testify in support of HB 538. I am now happy to answer any questions that you might have.