



House Bill 335 – Proponent Testimony
Ohio House Health Committee
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Chair Huffman, Vice Chair Gavarone, Ranking Member Antonio, and members of the Ohio House Health Committee, thank you for allowing me to be here today to provide proponent testimony for House Bill 335, which would designate April as Sarcoidosis Awareness Month in the state of Ohio. My name is Karen Van Kerkhove, and I am a registered nurse and clinical care nurse coordinator at the Sarcoidosis Center at the Cleveland Clinic.

In my role, I work closely with patients affected by sarcoidosis. I follow them from the time of their initial consult to our center, throughout the entirety of their care. Our goal for treatment is to provide a quality of life that patients themselves feel is livable, so that they are once again in control of their lives.

Sarcoidosis was identified more than one hundred years ago, and has been designated a rare disease with no known cause. It is an abnormal inflammatory response to a trigger. While healthy people have a defense response with cells attacking the intruder, individuals with sarcoidosis develop clusters of cells that form what is referred to as a granuloma, which can change the structure of the affected area.

This disease can affect any system of the body, and at times, several systems can be affected at once. For example, a person can have sarcoidosis affecting his or her eyes, heart and brain, while another person can have sarcoidosis affecting his or her lungs, skin, and bones.

Sarcoidosis can appear or disappear suddenly, or it can develop gradually; symptoms may even come and go throughout a patient's lifetime. While it is most commonly found in the lungs, it is not a requirement for diagnosis. The severity of the disease is based on the individual. Lung involvement can lead to lung transplantation. Cardiac involvement can result in sudden cardiac death, which is why these patients usually require a defibrillator. Skin involvement can have disfiguring lesions on the face which will sometimes force the patient to not go out in public.

Sarcoidosis is typically seen in individuals aged 20-50. It is nondiscriminatory in that it can affect any race or gender. The incidence is one to two Caucasians per 10,000 and up to four African Americans per 10,000.

Due to the difficulty in diagnosing sarcoidosis, many times the initial thought is that the patient has cancer, until the biopsy is completed and shows granulomas. Upon diagnosis, patients are left with a disease that many are unfamiliar with. Many physicians are left treating a disease they may not be comfortable with. That is where our center comes in.

The Cleveland Clinic Sarcoidosis Center is one of the largest in the United States. We manage patients throughout the country and world. We treat the patient based on his or her quality of life



and the organs involved. Treatment varies with each individual. Some will require no treatment, while others will need oral medications, injections, or monthly IV. As you can see, this disease is life-altering, which is why House Bill 335 is so important.

The Cleveland Clinic works closely with the National Foundation for Sarcoidosis Research (FSR), and Cleveland has been selected for one of their conference sites in 2018. There is also a Northeast Ohio Sarcoidosis Support Group that has great plans for April 2018. They include an FSR walk and a “paint the town purple” program where school age children will pay to wear purple for the day in order to raise money for the cause. We are also working on a Sarcoidosis Night at one of the Akron Rubber Ducks baseball games. All the money raised will be used for research on the disease.

There have been great strides made in the research and treatment of this disease, however it is still a lengthy battle to make sarcoidosis recognizable and adequately funded for additional research. House Bill 335 will bring us one step closer to these goals by having sarcoidosis spotlighted for at least one month out of the year.

The designation of Sarcoidosis Awareness Month will bring statewide attention to this disease. Cleveland Clinic hopes that Ohio will be on the forefront of pioneering not only the recognition treatment, and research of this disease. We thank the chairs, Representative Howse and Representative Lepore-Hagan, for introducing this bill and working with the Cleveland Clinic along the way.

Again, Cleveland Clinic supports House Bill 335 and urges the committee to be supportive as well.

Thank you for the opportunity to testify. I would be happy to answer any questions that you may have.