

Chairman Huffman, Vice Chair Gavarone, Ranking Member Antonio, and Members of the Health Committee. My name is Gwendolyn Fish, and I am an African-American diagnosed with sarcoidosis. I started researching this disease years ago and everything that was written about the disease started that it was predominantly in black women. Now, there are all kinds of supposedly theories on those who are affected with sarcoidosis. Let me explain what sarcoidosis does to the body.

Sarcoidosis is an inflammatory disease that can affect almost any organ in the body. It occurs when a person's immune system overreacts, resulting in the formation of granulomas, microscopic clumps of inflammatory cells. When too many of these clumps form in an organ they can interfere with how that organ functions. The disease is estimated to affect 200,000 Americans. While most commonly it is diagnosed in African American women ages 20-40, it has now been characterized in all demographics regardless of age, gender, or race. The cause of sarcoidosis is currently unknown.

My son, Sgt. Wilbur Lee Fish, Jr. had **no** warning signs. In April 2013, he had his annual physical at Ft. Detrick where he was employed as a biochemist. On May 11, 2013, he said goodnight to me, rolled out of bed and was dead at age 47 with **sarcoidosis**. He left a wife of 18 years and a 2-year-old son too, soon. Look at his pictures. He showed no signs of being sick. This is a silent, killer disease. I have included pictures of my deceased son for everyone to see what this is hurts Ohioans.

I was first diagnosed with sarcoidosis in my eyes and my lungs over 10 years ago. Then I went into remission for about 2 years. Through the years, I worked as a loan officer for a bank, a Claims Examiner and the director for different state & federal programs at the Youngstown area Urban League. In 2009, the disease returned. My health got worse. I could barely breathe but continued to work in the community and on my job as much as possible. I was since diagnosed with fibromyalgia, sciatica, neuro sarcoidosis, rheumatoid sarcoidosis, peripheral neuropathy in my hands and feet. In 2015, I had heart failure, three Strokes. In 2016, I was admitted for heart failure. Again, in 2017, I was admitted for heart failure & then admitted to Park Vista nursing home. I ache and I am in constant pain all day, every day. I am a community activist. However, due to this horrible disease, I cannot do as much as I once was able to do. I am on oxygen therapy that means I have limited supply of oxygen and cannot to do a lot. I get tired easily. I cannot walk very far, which means I need a wheelchair. I need a scooter to get me to meetings, where there is limited parking for the handicapped and in buildings that I need to visit to lobby for help for greater awareness, funding, and a cure for sarcoidosis.

Awareness plays a vital role in helping to bring much needed relief and answers to what this disease is does. So often, doctors do not take the time to explain sarcoidosis to a patient and what to expect or suggest natural alternatives. Support of this bill will help patients, support groups, and lobbying for research for a cure. Research to date has not been aggressive for a cure due to the lack of data. This has to change. Let us get a cure. What I know is that it is so costly to pay natural herbs to ease your pain and stop your immune system from shutting down. I was going to a nutrition center in the chiropractor, which helped tremendously, but it was out of pocket cost to me because the insurance did not want to cover the visits. Medicine today is not developed for

sarcoidosis.

Please pass this legislation, and consider legislating better and broader health coverage, hold doctors more accountable in diagnosing a patient with sarcoidosis, have the health departments do better reporting of sarcoidosis related deaths and report patients with sarcoidosis. We should give patients more relief with this disease through better health care, natural or alternative medicines, outreach and awareness, and support groups.

I am so sorry I could not make it for the testimony in person; however, I hope to get a scooter to enable me to be more independent.

Representatives Lepore-Hagan and Howse, thank you for introducing this important legislation. Chairman Huffman, Vice Chair Gavarone, Ranking Member Antonio, and Members of the Health Committee, thank you, and God bless you.