

Chairman Huffman, Vice Chairperson Gavarone, Ranking Member Antonio, and Members of the Health Committee. Thank you for allowing me to testify today about HB 335. My name is James M. Amey. I'm a 59 year-old white male, living in Canfield Ohio. I have a Bachelor's Degree, a few classes toward a Master's Degree, and two Associate Degrees. I retired from the USAF on Nov 1, 1993. While in the USAF I spent tours of duty in England and in the New England states. I retired from the Washington, DC area after living there for 19 years. I retired from the Washington Metropolitan Area Transit Authority (WMATA), on Oct 1, 2013.

In 1995, at the age of 37, I was diagnosed with Sarcoidosis in the lungs after a chest X-ray and subsequent mediastinoscopy – a small incision at the base of the neck (throat) while under general anesthesia, to gain access to diseased tissue.

There was not much information about Sarcoidosis and I soon discovered that the doctors that I was seeing knew very little about the disease or where else it might be located within my body. I was told not to worry unless the disease gets into my heart, and since I am white, that will not happen because Sarcoidosis only gets into the heart of black people. Several doctors assured me of this and though skeptical, I trusted their judgment. I was never put on any medication except for albuterol inhalers.

In 2008, at the age of 50, I developed a persistent dry cough. Months later, in July, I was taken to a hospital emergency room with sudden nausea, weakness and sweating. We thought I was having a heart attack, but subsequent testing ruled this out. I had an MRI of my heart and the results indicated that a large portion of my heart was affected by Sarcoidosis.

I was scheduled for surgery to receive a defibrillator, but the earliest surgery date was two weeks away. My doctors wanted to admit me to the hospital for close observation while I waited for the surgery. I declined. I was prescribed the steroid prednisone prior to and after surgery, for a period of eight months. On July 8, 2008, I received a Medtronic brand defibrillator. The defibrillator is attached to three wires that were inserted into my heart. The defibrillator has never fired. In Aug 2013, I had a replacement defibrillator, a Boston Scientific. The defibrillator has never fired.

Throughout this entire process, from 1995 when first diagnosed, through 2013 when I received my second defibrillator, my experience has been that even the most learned doctors in the Washington DC area know very little about Sarcoidosis. In fact, on numerous occasions I was told that the disease will not affect my heart because I am white. Even after my first defibrillator was implanted, I visited a long practicing internal medicine doctor who directly told me that I do not have Sarcoidosis in my heart. I pointed out my defibrillator as well as the written MRI and the MRI CD as proof. I also visited a world-renowned Sarcoidosis expert in Washington DC who wanted to study me, under my health insurance and at my expense, rather than treat me. I declined.

I never returned to any of these 'expert' doctors and I have had no success in finding a doctor who is knowledgeable about Sarcoidosis.

I currently see no specialist for my Sarcoidosis, nor am I on any medication. Unfortunately, there is no known method for accurately monitoring Sarcoidosis. Even the commonly used Angiotensin-Converting Enzyme (ACE) test is inaccurate. ACE levels are less likely to be elevated in cases of chronic Sarcoidosis and the test is only reliable in 25% of patients with a specific genotype. Therefore, ACE tests are unreliable.

Unfortunately, or to be accurate – tragically, Sarcoidosis does not receive the ‘credit’ it deserves for the kills it makes. Some other disease or affliction will be attributed to a Sarcoidosis-caused death. Pro football star Reggie White most likely died from Sarcoidosis in his heart, but cause of death was attributed to cardiac arrhythmia. Comedian Bernie Mac’s cause of death was listed as pneumonia, but he struggled with Sarcoidosis for 25 years before he died.

Until there is more attention paid to this disease and until it is properly listed as a cause of death it will stay hidden in the shadows and it will never receive the attention and study that it deserves. Therefore, it will keep on killing.

My current situation is to wait and hope and try to live my life.