

DR. BERNADETTE A. KUTCHER, D.O.
99 Todd Avenue; A5
Hermitage, Pennsylvania 16148
Phone & Fax: 724-342-4964
Email: drbkutcher@gmail.com

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House Bill 335—Sarcoidosis Awareness

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 Dr. Bernadette Kutcher. I am a Family Physician, however, my additional designation is this: ***I am a patient...a Sarcoidosis patient.*** I am able to offer knowledge on the disease as a physician who has dealt with countless sarcoid patients, and I am able to offer overwhelming knowledge and experience as a sarcoidosis patient. Please allow me to explain.

In August 1984, at the age of 31, I began medical school at The University of Health Sciences College of Osteopathic Medicine in Kansas City, Missouri. During my third year, I was diagnosed with sarcoidosis, but this diagnosis came with much difficulty. You see, as many sarcoidosis patients, I was first told I had cancer and would die before graduating from medical school. After surgery to determine the correct diagnosis, my physician came into my hospital room carrying an armful of medical books because he was not sure how to treat me. **This is the first step for you to understand about this disease...physicians are taught very little about it.** Prior to my diagnosis, in one of our classes, we were taught the following lines about the disease:

Sarcoidosis is a granulomatous disease. Cause is unknown. No cure. It usually affects the eyes, lungs, and skin. In the United States, it affects Blacks more than Whites. Sweden has the highest number of cases. Affects women more than men usually between the ages of twenty to fifty. Treatment of choice is Prednisone.

That was it! Thus explains why my physician came into my hospital room carrying an armful of medical books.

Over the rest of my medical school years, I had to take two leaves of absence because of escalating symptoms including fatigue, shortness of breath, pain, appetite changes, and heart rhythm irregularities, but I was able to graduate with my class in May 1988. (Note: my father died one month before my graduation.) Right after graduation, I was delayed in beginning my internship because I developed bone marrow involvement resulting in spending a week in an isolation room because my immune system was compromised by the disease. When I did proceed into my internship, I had to take two brief leaves of absence to deal with the aggravating symptoms. My fellow interns resented this resulting in an unpleasant year of training. Then came my Family Practice residency...exciting, fulfilling, but also suffering and the testing of my

endurance, integrity, and commitment. I developed brain involvement and was diagnosed with Neurosarcoidosis, which occurs in only about ten per cent of cases. My symptoms included weight gain and complex partial seizures resulting in the necessity of a five-month leave of absence. However, as bad as the disease effects were, more agonizing were the hurtful actions and disrespect of the other residents and program director because they failed to comprehend and appreciate the impact the disease was having on my body. Simply, they put me through hell. Instead of coming to me and asking what they could do to help, they questioned my integrity, my commitment to medicine, and my value as a human being. **Again, as stated above, limited education about sarcoidosis impacts how physicians treat those diagnosed with the disease...even their own colleagues.**

Through what I believe to be the Grace of God, I went into remission, finished my residency during which I was named Chief of Recruitment, and finally at the age of 42, I opened my Family Practice medical office. During this time, I was physician to many sarcoidosis patients from several states including Ohio, Pennsylvania, and West Virginia. I also created a local Sarcoidosis support group. I was witness to the impact this disease had on the lives of patients as well as their families. Some experienced very little problems and went on with their lives, but those with chronic sarcoidosis, experienced waxing and waning of the major and minor effects including overwhelming fatigue, breathing difficulties, dry cough, night sweats, fever, weakness, weight changes, joint and muscle pain, skin lesions, dry eyes or visual difficulties, hoarseness, headaches, facial nerve weakness, ringing of the ears, heart irregularities, and hormonal imbalances. The list of symptoms may include a simple statement, until proven otherwise, any symptom is sarcoid.

My time as a practicing physician was short lived. After only two years, my own sarcoidosis returned with a vengeance resulting in more weight gain, totaling almost one hundred pounds and increased brain involvement with worsening complex partial seizures and multiple deficiencies of vitamins and the hormones produced in the pituitary gland. At my worst, I was having up to five seizures a day necessitating protective caregivers as I traveled to multiple medical centers seeking treatments and a cure including Emory University in Atlanta, Georgia; Thomas Jefferson Hospital in Philadelphia, Pennsylvania; Massachusetts General Hospital in Boston, Massachusetts, both UCLA and USC in Los Angeles, California, and UPMC in Pittsburgh, Pennsylvania. It was while seeing one of the world's top sarcoidosis physicians, Dr. Robert Baughman, at the University of Cincinnati in Ohio I was given a poor prognosis and was put on a treatment protocol of the chemotherapy drug Cytoxan. I received this treatment by IV every two weeks for a little over three years. It needed that long to penetrate the protective barrier of the brain called the Blood Brain Barrier. During the three years, I experienced most all the horrible side effects of the majority of chemotherapy medications...nausea, vomiting, fatigue, weakness, hair changes, dehydration, and more weakening of my immune system.

Again the Grace of God intervened. I was left with a guarded prognosis, but I was still alive, and the seizures did come under better control especially after multiple trials of anti-seizure medications settling on the addition of a seizure medication called Gabapentin. But, the damage to my life and body progressed over the following years with many other disease complications and long-term chemotherapy side effects. I was near death multiple times with

one time occurring after losing one-half of my blood necessitating blood transfusions followed by on-going IV Iron treatments about four times each year since.

Once the sarcoid relapsed in my brain, my life has never been the same. I have never returned to medical practice. I lost an engagement for marriage. I lost the ability to ever have children. Because of the nature of the complex partial seizures, I lost friends and had to spend thousands of dollars to have protective caregivers that medical insurance refused to cover in spite of going to court to fight both Medicare and Blue Cross. (I used money from an inheritance I received after my sister and brother-in-law passed away four months apart.) Because of the pre-existing disease, I was unable to obtain professional disability insurance resulting in my eventual dependence only on Social Security Disability to live, which continues. Thus, the sarcoid wiped me out financially. I have lived a very frugal life learning a dollar can be stretched very far when necessary. For two years, I had also fought the Office of Vocational Rehabilitation seeking help to begin a writing career all to no avail even after winning a court case and appeal. OVR simply never complied.

Over the years, I have sought help from many government agencies, but mostly I have been told I do not qualify because of not being married, having no children, making too much Social Security Disability (even though I began at about \$900/month and at the present time, I receive \$1,300/month.), and my disease not being understood. Up to the present time, I have lived a very reclusive life, and besides the Social Security Disability, I receive \$15.00 in food stamps and about \$50.00 in heat assistance during the winter months. I have a minimum support system with God being my one true source of anything I need.

Over the years, I have had many individuals contact me from both in the United States as well as other countries including Australia, New Zealand, South Africa, The Netherlands, Canada, and the United Kingdom. I was able to lecture about sarcoidosis back in 1998 in London England at King's College Hospital...the very hospital where Dr. Jonathan Hutchinson discovered sarcoidosis back in 1860. The people who contact me seek physician referrals, answers to questions about sarcoidosis, but mainly, they call to have someone to talk to who understands what they are going through. Interestingly, I get asked two questions ninety-nine per cent of the time "Why does not my doctor know more about sarcoidosis?" and "Why does my doctor make me feel like a hypochondriac?" My answer covers both of these two questions...Simply, doctors are taught very little about the disease, and what they are taught seems to indicate that sarcoid is not that serious of a disease and not very prevalent. After all, most of the medical literature states in the United States sarcoid affects only 1-10 in 100,000 Caucasians and about 34 out of 100,000 African Americans with Japan, Sweden, and the Northern European countries having the most cases overall.

At this time, I am not cured. I am not in remission, but for the first time ever, I am somewhat stable. I have written two book manuscripts about my personal story with one being focused on my spiritual journey through the disease. I will soon begin revising these and then marketing them for publication. I have also completed a screenplay for which I have recently begun to approach contacts in Los Angeles for purchase and production. I still take calls from anyone needing answers or encouragement. I believe God wants to still use me as a physician, but in a different way. **My mission is to educate, inspire, and most especially, offer hope.**

Ms. Lepore-Hagan and Ms. Howse, thank you for introducing this bill and allowing me to share my knowledge and experience both as a physician and as a sarcoidosis patient. Please feel free to contact me with any questions you may have. Health committee members, whatever I am able to do to help you to help those of us with this disease, all you have to do is ask. Thank you for wanting to help.