

Yvonne Lewis-Holt

Yvonne Lewis-Holt is a 27-year survivor of sarcoidosis who advocated for herself to get the right diagnosis and proper treatment.



My name is Yvonne and I'm a 27-year survivor of sarcoidosis and a five-year survivor of breast cancer. My strong faith and strong will to live helped me survive and go through those hard and trying times.

My shortness of breath first started in 1978. One doctor said I had asthma, one said bronchitis, another COPD. I was treated for this for nine and a half years.

Then I met a new doctor. I told him my symptoms, and he immediately started doing tests. I had finally found someone that was going to do something for me. The doctor called me into his office to discuss the results. He said everything was normal, even the x-ray. I knew that couldn't be right, so I asked him what was causing my symptoms. He looked me in my eyes and asked, "Have you ever had psychiatric help?" I will never forget those words. In fact, they still ring in my ears. I left crying and still not knowing what was going on with me.

In 1993, I started a hacking cough. I didn't really pay any attention because I was a smoker. One day, I started coughing up blood. My first thought was, "OH MY GOD! I HAVE CANCER!" I was so scared! I threw the cigarette away, and to this day have never smoked another one. I ran into the house to tell my husband, and he immediately took me to see my doctor, who said I had a bad case of bronchitis, prescribed antibiotics, and sent me on my way.

I was working in a doctor's office at the time and started coughing at work. The doctor said my cough didn't sound good, and she called a pulmonologist, who said I could come right then. I left work and went to his office.

After everything I'd been through in the past, I wasn't looking forward to seeing him and hearing the same thing over again, but I went. After hearing my symptoms, he told me it sounded like I had sarcoidosis, but that to be sure he would have to do a biopsy of

the lungs. I agreed, and we set a date for a couple of days later.

After I woke up in recovery, the doctor came in and told me his suspicions were correct. I had sarcoidosis. He explained that I only had 40 percent of my lung capacity left. Had we found this sooner, we may have been able to prevent the lung loss from being as bad as it was.

He started me on a steroid, and after about two years that stopped working, so he tried several other drugs, before trying a steroid again. I was also on two inhalers. Nothing seemed to be helping me. I kept getting worse. The doctor said my only other option was the sarcoidosis clinic at Johns Hopkins. I agreed and found that when I got to Johns Hopkins, I had an appointment with the head of the department. I felt in my spirit that God had guided me to the right place at the right time.

The doctor talked with me about my history, ran some tests and started me on a new medication, which was a miracle drug for me. My body started feeling better in a week's time. I was really feeling great, breathing better and my spirit was really up.

In 2005, I'd been on that medication for about three years, when I started getting very tired and had trouble breathing. I was admitted to the hospital and into surgery to put in a pacemaker. My doctor said it was a wonder I wasn't found dead somewhere. God is so good!



After the surgery, I found out that sarcoidosis had attacked the electrical system in my body and affected my heart. They put me on oxygen 24 hours a day and diagnosed me with sleep apnea.

In August of 2013, a new doctor took me off my medication because I had been on it so long, and it can cause cancer. In fact, he took me off sarcoidosis medication altogether, because the sarcoidosis burned itself out..

I walked around on a cloud until it floated away from me. During my annual exam, my gynecologist found a knot. He did a biopsy and confirmed I had stage 3 breast cancer.

I opted for a double mastectomy. The surgery was successful and had gotten all the cancer. We were so happy about the news, and I started chemotherapy.

Chemotherapy was the roughest and sickest road I had ever travelled. I had treatments once a week, and always ended up in the hospital. After the fourth of six treatments, I was put in the ICU.

After all those years of believing God was going to heal me, my faith had dwindled. I prayed for God to take me if He wasn't going to completely and immediately heal me. I couldn't take that sickness anymore. It was too much. As soon as I said, "Amen" to my prayer, my pastor knocked on the door. After a short pause, he entered and asked me how I was feeling. I told him how sick I felt. We just looked at each other before he spoke and made me promise to fight physically, while he promised to fight spiritually. With the little mustard seed of faith I had left, I managed to get out, "I promise." He prayed for me and left to come back the next day. I was determined to keep my promise.

The next morning the doctor came in and told me they weren't doing any more chemo, because the amount I had done was enough.

My fights with cancer and sarcoidosis weren't easy ones, but if you don't give up and believe in your heart, trust God, and pray, I know you can beat anything! ■

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. These lumps are called granulomas. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart. Sarcoidosis varies in how active and how severe it is for each person and over time. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough that may lessen or go away over time in some people, but remain in others.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- Skin: Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp.
- Heart: Shortness of breath with activity and swelling in the legs. One may have an irregular or fast heart beat at times, or pass out without warning.
- The Nervous System: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain or a "pins and needles" feeling.



Learn more

ATS Patient Education Series.
"What is Sarcoidosis?" New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf>