

<http://www.rheumatic.org/judy.htm>

JUDY, scleroderma

For 25 years of my life I worked as a medical secretary doing transcription in medical records in two different hospitals and for 15 years of that time I worked in a doctor's office. I loved the work and especially liked knowing all the medical terminology - how to spell the words and what they mean. Spending lots of time in the medical dictionaries, Merck Manual and PDR, I had obtained a good knowledge of illnesses and the drugs used for them. All this information was of no use though. It wasn't like I could go out and write a prescription or even use the words in daily conversation.

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Who would know what I was talking about? And when faced with my own illness all the information I had was useless. You see, even with all this knowledge, I HAD NEVER HEARD OF SCLERODERMA. until I was diagnosed with it at age 51.

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I had Raynauds for about 15 years and knew that it could indicate more serious disease (just WHAT I did not know) but chose to ignore it and hope nothing more presented itself. My new physician noticed the Raynauds during a routine blood pressure checkup and ran some blood tests. We got an elevated SED rate and a positive ANA Titre (1:40,960). He sent me to a rheumatologist.

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As a Christian, I have a lot of faith in God and believe in answered prayer. My church family prayed for me a lot and I believed that God was going to bring healing to my body. (I was expecting INSTANT total and complete recovery). And YES, we do believe that He uses doctors, medicine and surgery to accomplish the work of getting us well.

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However as time went along my condition worsened. I began having more symptoms. Joint problems with my shoulders which led to a frozen right shoulder that had to be manipulated under anesthesia by an orthopedic surgeon (Actually they put you out and then just jerk the shoulder around until all the adhesions break loose) - very painful when you wake up and followed by weeks of physical therapy. (I called my physical therapist a physical terrorist!)

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The following year I went through the same thing with the left shoulder. My hands became weak and I couldn't make a fist. The Raynauds increased (I didn't ever have any ulcers though). I developed bands of tight, discolored, hard, thick skin around each forearm.

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The skin could no longer be picked up in folds. My face became tighter with more tingling, my mouth became smaller and smaller. I couldn't even open wide enough to bite into a sandwich. Chewing became difficult. My speech was affected. I developed ugly Telangectasis (red spots) on my face. My lips (what lips) became very narrow almost disappearing. Knee joints became painful, with loss of mobility and if all this wasn't enough, there was the fatigue, insomnia, depression and short term memory loss (brain fog).

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The fatigue was probably the hardest to deal with. I thought fatigue just meant you got tired quicker than average. Not it at all!!! You know it's a "fatigue day" the minute your feet hit the floor in the morning. Just total weakness and no strength. Every task is monumental. Can't vacuum or even load the dishwasher without rest periods.

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Pushing the grocery cart around the store is like running a marathon. I was hurting so much lying in bed at night that I would get up around 2 or 3 am. to get in the hot tub for awhile, then I could go back to sleep. This time in my life became the "time of the couch potato". I did save lots of money though as I like to shop and during this time I wasn't out there shopping.

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I am fortunate enough to have a very loving, supportive family and this along with the prayers was all that kept me going through this bad period. I also began having bouts of tachycardia (rapid heart beats) and hypertensive crises. I was hospitalized for one bout of the same in July 1994. My doctor

was out of town and the doctor who was taking care of me phoned his father (a cardiologist) for advice. He told me I had a lot of hard work ahead of me that I HAD TO GET THE SCLERODERMA UNDER CONTROL. This was the first time anyone had ever made a connection between the high blood pressure, tachycardia and the scleroderma.

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After I was home from the hospital I remembered a rheumatologist who had appeared on a local TV program about scleroderma. I went to see him and got more blood work and another lung function study. (This test is very stressful to me because of the difficulty (almost impossibility) of fitting the breathing apparatus into my very small mouth with no elasticity) But the results of the test were even better than the one I had before. The bloodwork showed no internal damage from the disease. Good News. He took picture of the bands of tight skin around my forearms (for educational purposes, he said) and I left with a prescription for Relafen. (I later developed a severe allergic reaction to the Relafen.)

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No one had ever said I needed any of the standard drugs for treatment of this disease - penicillamine, prednisone, methotrexate, etc. But I had already made up my mind that these were scary medicines and I would not want to use them.

Not too long after my last appointment with the rheumatologist, I received a phone call from a lady from Alaska who was visiting with our pastor. She is a RA patient who had heard about treating rheumatic disease with antibiotics. She was going to start the treatment just as soon as she

returned home from her trip. She told me about the book "THE ARTHRITIS BREAKTHROUGH" and the Road Back Foundation. I got the book, sent for the information and it all sounded good to me.

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" THE ARTHRITIS
BREAKTHROUGH" (the Road Back Foundation)

I called the rheumatologist's office to ask about the antibiotic therapy, but was told that No he didn't do that. I then took a copy of the protocol to my GP. He hadn't ever heard of it and I thought he seemed skeptical. However he said that since it wouldn't hurt me he could write the prescription for me (oral only). We chose doxycycline because in about 6 weeks I would be leaving for some short term missionary work in the Solomon Islands in the south pacific and would be needing to take doxycycline for malaria protection.

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This was the first ray of hope since I learned I had this disease. I took a blank picture frame and in one upper corner I have a pretty picture of flowers that says "EXPECT A MIRACLE!" The other side says "SOME PRAYERS ARE ANSWERED ONE DAY AT A TIME". The bottom section of the frame is left blank. I am saving that spot for a copy of the labtest report that indicates the scleroderma is in remission! And I KNOW that day will come.

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My mother has just recently been diagnosed with mixed connective tissue disease (I think they say lupus, scleroderma and myocitis). Her doctor is one I worked with briefly when I was a medical secretary so I visited him with her, took the antibiotic protocol , told him about my treatment and after looking it over he started Mom on doxycycline. She is doing much better.

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My story is not finished. I have a ways to go yet to complete recovery. Since I joined the Rheumatic Support Group I have learned so many things. One is about the diet that goes with the antibiotics. I hadn't known about it before. So at this time I am starting the diet and learning to drink lots of water. There are also supplements and I am just getting figured out what to take. Also there is a lot of mention that those with scleroderma need treatment also with IV Clindamycin. Because it is winter and we "get snowed in" a lot, I am going to implement the diet changes and continue as I am for a couple of months. Then I will begin to persue either talking my GP into trying the clindamycin, finding a doctor in Portland, OR who will do it, or traveling even farther if necessary.

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I am looking forward to complete recovery and when it happens I want to return to the rheumatologist who took pictures of my arms and show him the "before and after"! The purpose of this story is to tell you antibiotics work! It did for me and it can for you. Faith in God and lots of prayers will help you also. If you have this disease get some prayer support going for yourself and if you haven't done so before this would be a really good time to make God a part of your life. He can give you strength that you need to face this illness.

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