

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

YVONNE, scleroderma

January, 1998:

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My name is Yvonne Testerman and I was 10 years old when I was diagnosed with scleroderma, I am now 62 so you see I have dealt with this disease a very long time. Dredging up these memories has been a very difficult emotional trip for me. We all want to remember the good things from our childhood and some of my childhood days were not good. This trip to the past has given me a new perspective; I can see the hand of God through it all, from the diagnosis at such an early age to the present when I "found" the antibiotic treatment and in so doing found hope for a disease that for so many years there was no hope.

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I was raised on a ranch in southern Oregon with lots of space to run and ride horses. I was riding by the time I was five years old. There were lots of cousins and friends around to spend time with. At about nine years of age, I realized I wasn't running as fast as I had before and I seemed to be tired all the time. Then there was this tremendous itching on my right thigh. When my mother finally took me seriously she discovered a large, white, slick scar extending from my waist to my knee. It was so

hard it couldn't be pinched and the skin was so taunt it was sinking into the knee joint. So, mom decided to see if I had any more scars and discovered more on my back and some extending from the right elbow to the wrist. Mom was one who thought if she didn't think of bad things they would go away. My grandmother is the one who finally said to my mother, "You've got to see a doctor, these scars are creeping up to her hair and face." That gave my mother the nudge she needed.

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Our old county doctor didn't know what was happening to me, but he knew of a doctor in a larger town 20 miles north that dabbled in dermatology. So we made the trip to the "big city" to see Dr. Rhue. He was a very interesting person, the railroad doctor, used strong language and said exactly what was on his mind. My mother covered my ears a lot as he examined me and made the diagnosis. He prescribed gold shots every week. The shots were administered by our country doctor, so every Friday afternoon after school I walked to his office to receive the shot in my hip. I had to remember which hip we used from week to week so each had a rest. Still got lots of gold deposits in my hips and bent many needles. Remember this was way back in 1945 and very little was known about scleroderma and even less was known about treatment. I took vitamin A and C and calcium and my diet was very restricted. No sugar. That wasn't hard for me as we were just coming off the war years and sugar rationing so I didn't have a sweet tooth. Can't say the same thing about the gold shots though. They hurt!

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After two years on the gold shots the disease went into remission and I was given a rest. The itching stopped and the skin became soft and pliable, but I never regained the strength in my legs that I had before and I continued to contend with fatigue. Then, when I was 14, we were visiting friends in San Francisco and we went to the zoo. I felt very tired and had to rest every few feet and every joint in my body hurt. I thought I might have the flu. My sister and I spread our sleeping bags out on the floor to sleep that night and the next morning I couldn't get up. My dad had to help me off the floor and decided we needed to head home because I wasn't well. The next few weeks are a fog. I remember needing help to get out of a chair, to tie my shoes, to get in and out of the bathtub and if I fell, someone had to help me get up.

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A nurse in Australia was experimenting with a treatment for polio victims with physical therapy and hot baths. So my mother felt she could do this too. (Again, no doctor.) The hot baths really helped

with the pain, but I remember crying when I got in and out of the tub. Stretching exercises kept my hand and legs from tightening up and curling. Now that I look back on it, this was probably the best thing that could have happened to me. A doctor probably would have put me in the hospital or at least to bed and my body would have shriveled up. After about a year, I regained most of the movement in my legs and could get out of a chair without help. The pain had subsided and I felt almost normal.

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At age 23, a patch of scleroderma appeared behind my knee. It itched and was shiny white and hard. By this time I was married and had babies and I'm sure my husband was wondering what kind of a problem he had on his hands. Since Dr. Rhue had retired, I had to find another doctor. After some research we found a dermatologist in a small town 100 miles away. This doctor ran more tests and took biopsies and said, "Yes, you're right, you have scleroderma." This time I was treated with a steroid hormone. I have no idea what the name of the medicine was and at that time I wasn't asking questions of doctors. All I knew is that I didn't want gold shots again. The doctor warned me that I couldn't be on this medicine very long and I had to taper off when I quit. This time the disease went into remission in about six months.

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During the next few years I had my ups and downs. The fatigue was the main concern and it was very difficult for my family and friends to understand, because I looked so well. It was in the early 1970s when I learned about the United Scleroderma Foundation. Finally I knew I was not alone in the world. By joining this organization I received the first information about scleroderma that I had ever seen. I found out how many different types of scleroderma there are. My poor, sweet, father was appalled when he read the information because then he knew that I hadn't been putting him on and that I was really sick and was lucky to have survived. All he could say was, "I'm so sorry, we just didn't know what was going on." I felt so sorry for him because he took it all personally. From then on I took my health into my own hands and went on the search for a cure. During this time our three boys were growing up and I was developing a career of my own in banking and education. Some days were just plain tough.

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In 1985 we moved to Salem as I had been hired to organize a new office to coordinate education for banks and savings & loans. That winter my feet and hands gave me a lot of grief. I ended up with a bunion on the right foot and a crooked finger. My GP really got to me when he said, "Are you really sure you have scleroderma?" Then, he sent me to a rheumatologist in Portland. I found him very knowledgeable and kind, a refreshing change. But, he still couldn't treat me. He could relieve my pain and operate on my feet and knees, but little else. The medicines of choice were methotrexate and penicillamine. I decided against the surgery and the medicine and continued my search for a cure.

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Last spring, 1997, I received an invitation to attend a meeting of the newly formed Oregon Trails Scleroderma Support Group in Eugene. At the time, I was in a big flare and this invitation was a gift from heaven. At the first meeting one of the members, a medical secretary, reported how she was taking an antibiotic to treat her scleroderma with amazing results. I broke right in and said, "Wait, what did you say?" So, she very kindly repeated what she had said and explained how she went about getting this type of treatment. She explained that I must do my own research and read "the book". In fact, she loaned me her copy of "The Arthritis Breakthrough". I read the book and found the web page with the testimonies and the rest is history.

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Oregon Trails Scleroderma Support Group

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 "The Arthritis Breakthrough"
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With clues from members of both the rheumatic arthritis internet group and the scleroderma support group in Oregon on how to approach my doctor, I made an appointment. Some of the hints I got were - get the information to the doctor to read before your appointment, get a good rest the night

before, dress professionally and with authority, and become thoroughly educated in the protocol. I went to my appointment fully armed and ready for a fight. But, he had read the material I had left him and took the wind right out of my sails by being very cooperative. He wanted to put me on 100 mg. a day of doxycycline and I told him I thought that was too much. So he prescribed 100 mg. every day or every other day. He didn't want to do the IVs and that's okay, I was just happy to get the antibiotic without a fight. But, I quickly found that the 100 mg. every day WAS, as I thought, too much. I cut myself back to 200 mg. MWF and I'm feeling great.

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I also treat myself to a massage treatment twice a month and I try to stay on "the diet" as much as I can. I take lots of vitamins, calcium, and glucosamine. I do stretching exercises and take good care of my skin with lots of lotion. I have been on the doxycycline since June 11, 1997, and I feel better than I have in years. The first thing I noticed after starting on the antibiotic was that the pain in my hands was gone. Then, I noticed I had more energy than I'd had in years. I know that someone like me who has had scleroderma for so many years is not supposed to show such dramatic improvement so soon, but I don't mind being different. In fact, its kind of nice.

This is the first time in 52 years that I have had any hope that I can lick this monster that lives in me. I just hope my story will encourage someone else to try this treatment. What have they got to lose?

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