

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

LEANNE, scleroderma

My name is Leanne and I turn thirty-three years old this March. I have systemic scleroderma. I live in a little coastal town in South Australia with my nine year old son, Jeffrey. My story is a different one in that I was given an tetracycline drug in the early stages of my illness. Unfortunately, it was given to me for something else and I had no idea it could help the scleroderma.

3 33 가 . 9

My problems started thirteen years ago. I was very fit, happy and healthy. I ran every day and worked out with weights and also did shift work at a busy hotel. I went to donate blood one day and the blood just didn't want to come out but I thought nothing of it at the time. I began getting very lethargic and depressed. My body felt achy and I ran fevers. The glands in my neck became enlarged, and to relieve the pain I rubbed in Deep Heat. My tongue had a thick white coating on it and my mouth had a metallic taste. The skin on my face started changing and became very shiny. I soon started feeling lazy and stopped exercising. My doctor said there was nothing wrong with me and perhaps I needed to see a psychiatrist. I felt like a hypochondriac.

13 가 .

가 . 가

가

.(

?)

The next thing I noticed was that my hands became swollen and shiny and my fingers would turn blue and feel numb. Soon I began developing ulcers on the tips of every finger. This made it difficult to work as barmaid, always touching cold glasses and making frequent trips to the cold room. I also had to give up netball as I was too exhausted and kept dropping the ball when it hurt my fingers. I felt unusually cold all the time and my feet felt like big lumps of concrete. My shoes always hurt. I couldn't understand why I always felt tired and kept telling myself to "snap out of it".

Then came the reflux. Whenever I bent down or lay down, I experienced an unpleasant, burning sensation rising up to my throat. My stomach always felt queasy. It was confusing and frustrating. My doctor told me it was all stress and that the ulcers on my fingers were caused from pouring beer at the pub. I was given a very expensive cortisone cream. It was useless. Also, by this time, I noticed hundreds of tiny red spots appearing all over my face. I wasn't a pretty sight and I began getting very depressed and moody.

가

가

)

() 가

)

가

가

(7

" "

가

()

(

It was then that I was finally diagnosed. My usual doctor had an accident, and, in his absence, I consulted his relief doctor. This doctor recognised my symptoms at once and sent me to a specialist who, after running some tests, confirmed I had systemic scleroderma. To be honest, it was a relief. Finally I could say that there really was something wrong, and it wasn't all in my head.

가
()
가 가 가 가
가 가
가

My ANA test came back "equivalent to a titre of 4,200" which was incredibly high. An endoscope was performed (I had to swallow a small camera on a long tube). The result was that I had a completely ulcerated esophagus. I didn't really understand the medical terms, but I know that heartburn took on a new meaning to me. I was given Zantac to take long term. These tests were performed in June 1987.

ANA "4200" 가
(가)
Zantac() 1987
6

I was given a drug called Adalat which thinned my blood and opened my veins. I soon gave that up as it made me feel worse. They also discovered my thyroid wasn't functioning, and I take oroxine to replace the missing hormones made by the thyroid gland. I moved back into my parents' home and had to give up bar work. I virtually lost interest in life and spent most of my time lying on the lounge. I decided to go and stay in Darwin (a more tropical climate) to see if the warmer weather would make me feel better.

(Adalat)

oroxine (?)

가

Darwin (,) 가

I went to visit my doctor to get my prescriptions up to date before I headed north. He suggested that I take a bacterial antibiotic called Vibramycin (doxycycline). This was to be a preventative measure for me, catching any bugs while I was up there. He also informed me that it might clear up my spotty face. I was told it was safe to take it long term and I think the dose was 50 or 100mg daily.

가 가 () 가 () 가 가

50mg 100mg

I spent five months or so in Darwin, and came back a different person. My symptoms were virtually gone. I felt wonderful. The doctors were amazed, thinking the warmer climate had done it. Now I look back, I'm sure the Vibramycin knocked out a lot of the disease and prolonged my life. Unfortunately I didn't realise this back then. I continued the Vibramycin for about another five months, until I fell pregnant. I had a good pregnancy, symptom free, and gave birth six weeks early to a healthy son.

Darwin 5

가 (, copy)

Not long after, the scleroderma once again showed its presence. Well, to cut a long story short, I slowly got worse. This time I didn't get sick so rapidly - it was more gradual. My son is diagnosed as ADHD so I had a hard time keeping up with him. It hasn't been easy and my doctors never told me much about my disease. I never talked about it and a lot of my friends didn't know anything was wrong. I hid my disabilities and wore lots of makeup. I made excuses when I was too tired and exhausted to go out. Even holding a conversation sometimes wore me out. I nearly became a hermit and some of my friends don't see me anymore. I hope I can explain it to them one day. Scleroderma is a lonely disease and I found it hard to explain what it was or how I felt to people. If you told someone you had cancer, then they'd understand - but scleroderma, no-one's heard of that. Well, that's what I thought anyway.

ADHD
(?)
가 가
가 가 ()
가 가
가
가
가

Scleroderma hasn't taken away all of my capabilities, but it stole the enjoyment of life from me. When I look back at major events in my life, Christmases, birthdays, weddings etc. I always remember how awful I felt physically on that day. I found it difficult to use certain parts of my body for long periods. For example, I could only vacuum one room at a time, then do something different for a while as my arm would ache too much. I do dressmaking, and design and make children's clothing and school uniforms with my mum. I always felt guilty on these days - guilty and useless.

My digestion seemed very sluggish and food appeared to sit in my gut for days.

가
가
) 가
()

Every morning I'd have a temperature, but this usually went away after two hours or so. My mouth and eyes were dry most of the time. I couldn't bear the cold and yet the heat never made me feel much better either. I found it hard to concentrate or focus on anything for long. My head felt fuzzy and vague. I ached all over. I was given anti-depressants, yet they never seemed to help. The depression is very hard to describe. Although I suppose it seems I had a lot to be depressed about, I'm not the type of person to worry. This was different - it hits you instantly and can last for hours, days, even weeks. It is very severe and very hard to fight. I found it easier just to let it take its course and not to try to achieve anything. It disappears as quickly as it comes and it was hard to understand.

2

가
가 anti-depressants ()가
가 가

I've experienced some "one off" effects from the scleroderma. Once, my left jaw locked up. I felt a tingling sensation in my lips, and couldn't close my mouth properly. The pain was incredible. I was given morphine and a muscle relaxant. It corrected itself soon afterwards and was very strange. On

another occasion, I can remember not being able to kneel as it felt like a big long needle was piercing my knee.

가 " 가 " .
() 가
() 가 .

This lasted for months, then disappeared. I never liked to complain much. I've seen some sad suffering of loved ones who have now passed on. I've lost two aunties in their early forties to cancer. My nanna and poppa died of cancer, one of my uncles is currently fighting bowel cancer and I lost my fifteen year old cousin to cystic fibrosis.

40

가

15

(囊胞性)

I thought scleroderma was nothing compared to these illnesses. I still had my independence, and although my symptoms were unpleasant, I was able to cope.

가

About four months ago I was very ill. I hadn't been able to swallow properly and was living off soggy breakfast cereal. My nose was constantly blocked and I couldn't smell or taste. My mouth was very dry and my gums were detaching themselves from my teeth. My teeth were very sensitive and one even crumbled. My eyes looked sunken and black. My cheekbones stuck out and my complexion was pale but covered in red spots. I know it's only vanity, but I hated the way I looked. I got my hair cut really short as it became brittle and lifeless.

가

(가)

Sometimes handfuls of it would come out in the shower. It began to become difficult to apply makeup, as my facial skin was so tough the foundation appeared to slip off. The skin on the soles of my feet came off, revealing raw flesh. In the mornings, I couldn't feel them, then after a shower the circulation would improve, causing them to bleed. I'd wrap them in gauze and walk on tippy toe. This put enormous strain on my calf muscles and they'd go into spasms and cramp up. I'd also get painful cramps in my side, causing me to double over in pain. Severe stabbing pains under my shoulder blades and an all over intense itching sensation kept me awake at night. I had a constant, thick, fuzzy head and began suffering blackouts. I was scared that I was going to die, yet didn't know how I could keep living feeling this bad.

가

가

()

()

()

가

가

가

My specialist ran some tests and informed me that he thought I should have died years ago. I appreciated his honesty. He suggested a blood transfusion and maybe amputating a severely ulcerated fingertip. He wanted me to start taking a drug called Plendil-ER (felodipine). I got the script filled but couldn't bring myself to take it as I knew the side effects would make me feel worse.

I never took cortisone or any of the drugs other sufferers talk about. I realise now that this was to my advantage.

가 , 가
가 Plendil-ER (felodipine)
()

My neighbour showed me an article in a magazine. It was about a girl called Janene thanking her mum Chris for finding help for her scleroderma. I phoned Chris, and when she explained the infectious theory to me it all made so much sense and I'd never been offered a better alternative. I read the book "The Arthritis Breakthrough" and related to everything Dr. Brown said. I wish he were alive so that I could thank him for saving my life. He was treated so unfairly but at least his years of work are being recognised a lot more now. It's a pity he isn't here to see this. I no longer feel alone with my illness and look forward to getting better.

Chris , Janene 가 Chris
Chris 가
() " The
Arthritis Breakthrough" 가
가
가

It wasn't easy to get a doctor to prescribe. Both my doctor and specialist were against me using this treatment. I had to find another doctor who was willing to help me. At first I was angry, but then I learned of the medical politics and the big drug companies and I feel the problem basically boils down to money. Well, I'm not prepared to be ignorant and die just so that the rich can get richer. I

wish more doctors would face the fact that this treatment works and tell their patients about it. Early diagnosis and treatment would stop this disease and people wouldn't need to suffer unnecessarily.

가 . 가 . 가 . 가 .

I began taking minocycline. I started at 50mg Monday, Wednesday and Friday, and have gradually increased it to 200mg Monday to Friday. On Sundays I take 1200mg clindamycin orally in one single dose. I haven't had much luck in getting this administered through IV. Maybe oral will be sufficient - I'm not really sure.

. , , 50mg .
가 200mg .
1200mg . ()
() -
... ..

Within the first two weeks I had some dramatic responses. The first was that my left thumb became swollen and inflamed. I couldn't bend it. My friend thought it could be broken, but the next day it was normal again. About a week later, the same thing happened to my right ankle. It felt as though I'd been kicked there really hard, but the next day it felt fine. These responses were Jarisch Herxheimer reactions, meaning that the antibiotic was reaching its target. Although I probably felt worse in the first month, it really wasn't that bad.

2 . 가 .
가 . 가 .
가 . 1 .
() . 가 .
(Jarisch Herxheimer reactions)

가 (,)

I can honestly say that I feel much better now. My head feels clearer and I no longer have blackouts. My swallowing has improved and I'm eating better. The most amazing improvement is that my reflux problems have totally disappeared. I noticed this soon after I began taking the clindamycin. I had to skip the clindamycin for one week as I was taking 1500mg daily of penicillin to treat tonsillitis. My heartburn came back that week, but as soon as I took the clindamycin the following week, it disappeared again. I have stopped taking Zantac and the anti-depressants. It has taken about two months, but I've noticed the depression has improved and now it's not as frequent or severe. Now I know that Dr. Brown said that depression is part of the disease, it's easier to understand. The depression is physical and not mental. I still tire easily and don't have much energy, but I realise that this treatment takes time. I'm having good days in between the bad ones, and on the bad days I don't feel anywhere near as bad as I did before taking antibiotics. I still have dark eyes and a spotty face. I've noticed that the Raynauds isn't as frequent, but it is summer here. I'll notice any changes in my body temperature this winter.

()

가

1500mg

1

가 ()

가

가

가

가

I am taking the following vitamins daily:

Vitamin E - 500IU once daily

Zinc - 30mg once daily

Manganese - 200mg once daily

Magnesium - 500mg three times daily

St. John's Wort - 2000mg daily

Vitamin C - 2000mg daily

Multivitamin and mineral supplement

Aloe vera juice

Acidophilus

Vitamin E - 500IU once daily

E 500IU

Zinc - 30mg once daily

30mg

Manganese - 200mg once daily

200mg

Magnesium - 500mg three times daily

3 500mg

St. John's Wort - 2000mg daily

St. John's Wort (?) 2000mg

Vitamin C - 2000mg daily

C 2000mg

Multivitamin and mineral supplement

Aloe vera juice

Acidophilus

()

I also drink lots of water and eat lots of vegetables. My digestion appears to have improved. I've had no bad reactiosn to the antibiotics. The clindamycin leaves a bitter after taste in my mouth, but that's nothing.

가

Over the years I've had about three ear operations, three nose operations and root canal treatment on my teeth. I read that some of these are common in a lot of scleroderma patients and I wonder if that is what started the disease.

3 , 3 (?)
가
가

I have shared my story to help anyone trying to decide whether to try antibiotics or not. I would have to say for you to go for it - what have you got to lose compared to what you can gain? I also plan to make more people aware of this treatment, and I know this is difficult when some doctors won't believe in it.

가
.
.

I would like to thank everyone in the group. Your stories have given me so much hope for my future. In particular, I'd like to thank Chris, whom I've never met in person, but we constantly phone each other. She has helped me so much and I'm so grateful. Also, another Chris who lives near me, has given me heaps of information and advice. I would also like to say thankyou to Ethel, who has helped me via Chris. You are all so wonderful and kind, and very much needed and appreciated.

Although I've suffered with scleroderma for around thirteen years, I believe I have been lucky. I've had two chances, the first was taking the tetracycline for another purpose, which I firmly believe saved my life ten years ago, and now, once again, I found it just in time. Despite everything, I'm happy with my life. I have a caring family and a wonderful little boy, and my health is on the mend.

Chris

Chris

Ethel

Chris

가 13
가

10

가
가

Leanne, South Australia.

You can reach me by telephone at Australia 0885 542 247

0885-542-247 ()