

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

JEAN, scleroderma

JEAN

Anyone with scleroderma needs to get on the antibiotic protocol as soon as possible. I don't want to frighten anyone more than I know they already are, but I can testify that scleroderma can get to your organs very quickly, no matter which form of scleroderma is diagnosed.

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Let me give you a time line of my wife Jean's scleroderma experience:

Jean

Sep '96 - Pain and swelling in hands, swelling in feet. Blood pressure normal.

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Oct '96 - Diagnosed with limited scleroderma, the least serious kind, probably would only affect her hands, forearms. BP normal.

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Jan '97 - Diagnosis confirmed by specialist, limited scleroderma. BP 150/88.

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Feb '97 - Rheumatologist followup. BP 160/94.

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Mar '97 - Flu symptoms, saw a general practitioner. BP 210/120. Prescribed Zestril for BP.

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Mar '97 to Apr '97 - Every test imaginable; heart, lungs, kidney flow, x-rays, scans, echos, ultra

12th May '97 - Dialysis begun.

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Now, on about 13th May '97 I made my first inquiry on the internet, looking up anything I could find on scleroderma. I almost immediately found The Road Back Foundation, got the books, subscribed to the site here, and immediately began getting encouraging messages from group. I did more homework on the antibiotic protocol, and within about 4 days I knew we were going to do the protocol as it was the ONLY thing that offered the possibility of a remission or possible cure. BOOM, Jean's in the hospital on 18th May, again on 24th May and I'm in a panic. I get frantic on the net because these great people are our ONLY hope. I even talk to the rheumatologist and the nephrologist in the hospital about the antibiotic protocol....and of course I get the eyes rolling in the head routine. But I tell 'em we're doing it and the rheumatologist was kind enough to prescribe doxycycline immediately. So we began the antibiotic protocol on 28th May '97.

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Road Back

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Jane 5 18 5 24

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Jun '97 - Trip to Dr. Sinnott in Iowa.

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Jun '97 - Began intravenous clindamycin (Cleosin) 900mg, twice a day, Monday to Friday (five days). Then 900mg once a month since.

97 6 - 900mg

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1 1 900mg

Jun '97 - Began minocycline (Minocin) 200mg Monday Wednesday and Friday.

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Aug '97 - Jean notices her hands are softer, not near as shiny or swollen and don't hurt near as

much, skin on her forearms is pink and normal looking again. I'm hopeful but skeptical. Could the antibiotics be working?

97 8 - Jean

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Oct '97 - Jean notices that the hard, "plastic like" skin on the rear of each thigh is gone!! She discovers this by unthinkingly bending down when previously she couldn't! Also since about this time frame, she can wear her wedding ring again! No excitement here!! Maybe the antibiotics are working?

97 10 - Jean

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Nov '97 - Continuing blood tests show improving kidney functions, at about 8% residual clearance, up from about 2% clearance.

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- 2% clearance

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8% residual clearance

25th Nov '97 - Latest blood tests show residual clearance at 16%. Two days before Thanksgiving, Jean is OFF dialysis. This doesn't mean her kidneys are cured, only that they're better, and getting better by the day. This could reverse of course but we'll ride this big horse as long as we can. And you should see her face beam!! Am I a believer in the antibiotic protocol? You can bet your Grandkids on it!

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16% residual clearance

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Jean

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26th Nov '97 - The present day. As I sit here waiting for the Grandkids to spend the night with us before Thanksgiving, I know that 4 year old Haley will at some point ask, "Are you still sick Mu-Mu?" And I know Jean will say "Yes, Punkin, but I'm getting well!"

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Thanksgiving

4 Haley 가 가 " Mu - Mu ?"
Jean " Punkin ,
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To all our great "net" friends out there, this is the update on Jean's progress I've been promising.
Please understand my reluctance to crow before I was ready. I'm ready now!!

, Jean . 가 가
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Hank & Jean Smith
Niwot, Colorado

You can reach us at hanksmith@attglobal.net
hanksmith@attglobal.net .