

MY RELATIONSHIP WITH RSD HAS CHANGED over time. Before I was diagnosed and was going from doctor to doctor, I was terribly frightened. I was experiencing intense pain and symptoms that made no sense either to me or to the doctors I was seeing. Finally after several years, I was given a diagnosis. I had a disease that some doctors knew about, that others were suffering from, and for which there were treatments available. Despite my suffering, I was hopeful.

Armed with a diagnosis, I visited the web and found RSDSA. I went to a symposium in Atlantic City—it seems like eons ago—where I met others like myself, heard doctors speak about RSD, and connected to some very special people. My life was really beginning to look up, and for the first time I felt that I would find a doctor with a treatment plan to help me.

When I finally found a doctor knowledgeable in RSD, I was amazed at how many treatment options were available. I read as much as I could. The RSDSA newsletter and website were invaluable. There were so many stories of others with RSD who, while not cured, were able to resume their former activities with much lower pain levels. If they could beat this thing, then so could I.

As the years went by, I tried every treatment I could find, short of ketamine. Some would help for a day or so, and some not at all. Instead of getting better, things got worse. One day I woke up and realized that I was no longer 45, but somehow was now in my 60s. I was battling arthritis, severe osteoporosis and breaking bones. I spent long stretches in a wheel chair, although most of the time I used a walker. The RSD had spread to both legs and with the added years, having the energy to wheel myself around was getting harder. There were no longer new treatments to try, so maintaining an optimistic outlook became more and more difficult.

Just when I thought things couldn't get any worse, I developed an autoimmune disease. The first obvious symptom was



## When RSD Hits a New Phase

*By Linda Lang*

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when I developed vasculitis on my legs. My body was attacking my own skin, becoming gangrenous and exposing the nerves in large areas where there was no longer skin to protect them. I had thought

the pain from my RSD was the worst pain I could feel, but this was much worse. I have had many operations to clear away the gangrene, but unfortunately, the affected areas covering the initial site of RSD will not heal, and I will need skin grafts. To my many RSD medications, I have now added prednisone and methotrexate; the methotrexate is an immunosuppressant drug used for cancer. It suppresses the immune system and leaves you open to all kinds of infections.

I now spend a lot of time in bed because walking is so difficult. My lungs have also become involved and dealing with both diseases can be overwhelming. I have only spoken to one other person who is dealing with the same issues I am. Not much data has been collected about what is happening to those who have long-standing RSD, and who are now into our 60s or older. I'm sure that there are others out there like me and I would sure love to hear from you.

RSDSA has done a wonderful job supporting those who are newly diagnosed or have suffered for a few years. We can now gather information from those who have had RSD for over 10 years and have not found relief, and are experiencing the normal problems of aging, or developed other serious diseases. We can begin to have the same support for this segment of RSDer's as well. We can share information on how each of us manages to cope (or not) with this new phase of RSD, which might go a long way to ease our suffering. It also can give doctors new information about the directions RSD takes to help us better. Please help us to help you. E-mail your stories. Remember how you felt when you were first diagnosed and got to meet or hear about others who were experiencing the same things as you. I know for me it eased the feeling of being alone in this battle, and gave me so much comfort and hope. With your help, we could do the same thing again for those who are finding it so much harder to be hopeful! ■