

Support and Awareness by Sharon Kodnik

My name is Sharon and I live in Nairobi, Kenya. In 2007 August I was having a tingling sensation in my fingers. When I talked to my friends about it they said that it must be rheumatism, but the tingling sensation became pain. I went to see a doctor, the doctor did tests, and he said that I was having a problem with my nerves. Then I went to see a nerve specialist and he did more tests and said that it was my thyroid gland under-producing. He put me on Thyroxin for a month. The pain didn't go down.

I emailed my aunt in the United States, in Texas, and told her what was going on. She is a pharmacist and her husband is a pulmonary specialist. She called me right back and said that I should try and get there as soon as possible. This was on a Saturday, and on Wednesday I left for the States wondering what was wrong with me.

I got to the States and five days later I couldn't do anything for myself—I couldn't even brush my hair, and the pain in the fingers was excruciating, and I seemed to have pain all over my body. Test, tests, and more tests were done and we found out that I had Lupus and that my kidneys were only working at 50 percent. I was quickly put on prednisone, 60 mg per day, and IV Cytoxan, 1 gram a month for six months. During this time I talked to the doctors a lot and I read a lot on the Internet to find out more about my condition and how to deal with it. After being away for three months I decided that it was time to come back home and start my new life. The doctors were a bit worried about me coming home so soon, but I felt that I needed to come home and start a support and awareness group.

I wrote two articles, one for the *Lupus Now* magazine and another in one of our local magazines. Other Lupus patients called me and we would talk, and I realized that there was great need to start an awareness and support group. I talked to the doctors and found that it was something that they were all willing to see happen.

I decided to start the group, and I told everyone that I didn't want it to be a Lupus patients' group only; I wanted to involve those near and dear to them, too, to help them understand Lupus. The main hospital has allowed me to hold the meetings in one of their meeting rooms, and all the other major hospitals have let me put up posters saying that there is Lupus awareness and support group. Already I have 20 members in the group, and that is before I started putting the posters up. I know that the number will grow.

My aim with the group is for us to give support to each other and to be able to create the awareness all around, and also have the doctors come in and answer questions. Many of us are on certain drugs for life and the pharmaceutical companies support us by giving us drugs at subsidized rates.

Being a third world country we need all the help that we can get. In Kenya we only have one Rheumatologist, and many people have been misdiagnosed and many have died due to lack of knowledge. We would like for other Rheumatologists to come in from other developed countries to help share their experiences and knowledge and volunteer services. Lupus, as we all know,

affects different organs of the body, so if doctors who have dealt with Lupus patients came and helped educate the nephrologists, cardiologists, gynecologists, pulmonary, oncologists, ophthalmologist, even nurses, the knowledge would be a great step forward.

I would like to make a difference. I would like to save lives. I cannot do this on my own but I know that if we hold hands we can make that difference together.