

# Living With Pityriasis Rubra Pilaris

Lorna Roberts

*Dermatology nurses and other health care professionals may sometimes fail to appreciate and recognize the physical and emotional challenges faced by patients with a particular chronic dermatologic disease or condition. To better bring patients' feelings and perceptions into focus, the Dermatology Nursing Editorial Board is excited to introduce a new series, "Patients' Perspectives: Living With..."*

*The goal is that these important patient views and comments will improve patient care. If you know of a patient who would be interested in sharing his/her experiences with the dermatology nursing community, please ask him/her to briefly answer (3-5 sentences) the questions as outlined here. Submissions can be sent via e-mail to the journal office at [dnjrnl@ajj.com](mailto:dnjrnl@ajj.com) or mailed to Patients' Perspectives, Dermatology Nursing, East Holly Avenue Box 56, Pitman, NJ 08071-0056.*

**When were you diagnosed with your disease/condition?**

I was diagnosed in October of 2001.

**When and how did you find out you had the disease/condition?**

I was referred to the dermatology department at Oregon Health Science University. I found out I had the disease from my appearance and skin biopsy.

**How would you describe your appearance?**

I would say I was a big, fat, red woman.

**What kind of education and support were you given at the time of your diagnosis?**

I was admitted to the hospital. I was not told much at all about the disease. I was told it is an exfoliating skin disease, and runs a course of approximately 2 to 3 years.

Lorna Roberts, is a Retired Nurse, Eugene, OR.



*The author in July 2002, 9 months after diagnosis of PRP. She removed her nitrile gloves for the photo. Notice thinning hair and red color of entire skin surface.*

I listened to what the dermatologist was pointing out to the students regarding my presentation. I listened to what he said about the disease. Other than that, nothing more was said.

**How has your disease/condition affected your life, physically and emotionally?**

The first 7 months were the most challenging. I was dark red, exfoliating about a cup of skin a day. I had to take two showers a day, completely cover my skin with ointment. I would then get into a sauna suit, which fortunately I could wear beneath clothing. In order to be able to use my hands, I wore nitrile gloves. I was freezing cold; I wore long-sleeved cotton tops and a sweat shirt over that. I wore long pants and cotton stockings. On my feet I could only wear slip-on slippers because my feet were swollen and had such thick skin on them. Fatigue was a problem. For over a year, I had about 5 hours of good life before I hit the wall everyday. I could not sleep and had terrible insomnia, which may have contributed to the fatigue. My scalp had horrendous flaking and constant itching. I had to wear light-colored clothing so the dandruff would not be noticed.

**What would you like health care providers to know about treating people with your disease/condition?**

I would like health care professionals to learn about the disease, and be able to talk to the patient about the disease. I would have loved something to help me sleep, but that was not forthcoming. Health care providers need to know what the patient should anticipate or experience and provide that information up front.

**What worked for you and what didn't (treatments, emotional support, etc.)?**

Treatments, since not much is known about the disease, are not really established. Apparently it is not really known if the disease responds to specific treatment or runs a course regardless. For me the sauna suit was a godsend, and I used the nitrile gloves. Also, I used lots of Cetaphil® Cream. I still use it daily. Cotton clothing, fleece sweatshirts, and tea tree shampoo helped. I am not sure what did not work because I tried a lot of products. I had good support. Emotionally, I did well. I found a great deal of support and information when I joined the PRP Support Group. They have a Web site with a lot of useful information ([www.prp-support.org](http://www.prp-support.org)). Without this group I would not have had a clue of what to expect. They also provided helpful hints for comfort measures.

**What do you wish society knew about your disease/condition?**

The disease is not contagious. I will not stay dark red. You can talk to me.

**What would you tell other people who are newly diagnosed with this disease/condition?**

I would and *do* tell them, "You will get better, it will take about 2 years to be clear. You will feel very tired, you will have swelling of your hands and feet, and you will have very thick skin that looks like wax on the palms of your hands and the soles of your feet." I tell them about the sauna suit and the nitrile gloves. I tell them what worked for me at the different stages. I tell them it took me about 17 months to notice any significant change in my skin, but once it started clearing it cleared rapidly. I tell them to keep active. What I was not told was that my ears would plug up with skin, and I would need an ENT specialist to vacuum my ears. I should have been told never to put water in my ears. Also, keep nails trimmed short because all the skin builds underneath your nails and is painful. I could not grasp, so opening jars or other containers was impossible without a pair of scissors or another pair of hands. Either the disease or the medication or both cause cataracts, so eyesight can be affected. You will lose most of your body hair.

**How do you think living with this disease/condition will affect your life in the future?**

I know I have PRP. I do not think it will affect me much if I continue to not get as sick as I was and have to spend 2 to 3 years getting well again. Right now I am in remission. I have a few red spots that appear now and again. I treat them locally with a steroid ointment and they go away. I developed a cataract that had to be removed, and I have a painful joint in my foot that can be annoying. ❖