

Living With Pityriasis Rubra Pilaris

Ralph E. Gilmore

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 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 unofficially in January 1998. Biopsies in July 1998 determined that it was pityriasis rubra pilaris (PRP).

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

It started in August 1997. Initially, I was diagnosed with having erythrodermic psoriasis. In January 1998, another dermatologist said he couldn't be sure what was wrong until biopsies were taken, but thought that it could be PRP. The reason for the delayed determination of PRP 6 months later was because dermatologists could not find any "clear" areas on any part of my skin/body to take the biopsy.

Ralph E. Gilmore, is a Retiree from American Airlines, Arlington, TX, and can be contacted at yo-boy@sbcglobal.net

How would you describe your appearance?

My entire body was red (like a bad sunburn); my skin was peeling and "powdery;" legs and feet were swollen (see Figures 1-4). I lost my finger and toenails twice. I lost all my body hair and most of the hair on my head.

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

My dermatologist (Dr. Alan Menter, Dallas, TX) informed me that PRP was a very rare disease and that only about 400 people a year were diagnosed with the disease. He stated, on average, that PRP would last from 2 to 3 years. He saw me every week for about 1 month, and then every 2 weeks. As I progressed, the visits were less often. He was my main support and he gave me his personal telephone number in the event that there was a drastic change in my condition.

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

Although I had very little pain, there were other physical problems I encountered that made my life miserable. Due to the disease and medication, I had blurred vision and the dryness in the eyes caused a permanent wrinkled cornea. I temporarily lost my hearing due to build-up of dry skin inside the ear canal. My entire body itched and I had to moisturize at least four times a day. Due to the redness, I was losing the heat in my body and I had persistent chills. While sitting still, I could feel my "pulse" or "heart beat" as a heavy throbbing in my body, neck, and head. My skin was sensitive. The leathery skin on my hands precluded me from even making a fist. My feet were the same and I had difficulty walking. I lost about 30 pounds. I was depressed, but not to the point of taking medication. I am a competitive golfer and could not play golf for over a year because I was physically and mentally drained.

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

PRP is so rare that most doctors have never heard of it. My dermatologist presented me as an "unusual case presentation" at a dermatologists' conference in 1998. Of the 25 dermatologists present, only two had seen an actual case of PRP. With health care providers in an environment of dermatology, I wouldn't expect them to know much about this disease. However, if a patient has this disease or any other rare disease, I would suggest that they research the disease as much as possible. Because of my condition, I had to educate the peripheral physicians

Figure 1.

Left arm. Remnants of PRP on arms; same distribution occurred throughout the body.



Figure 2.

Right arm. Islands of skin not cleared or healed.



Figure 3.

In 1999, after 18 months of PRP.

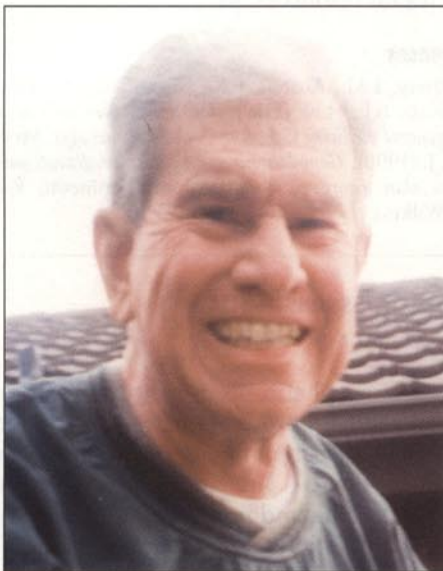
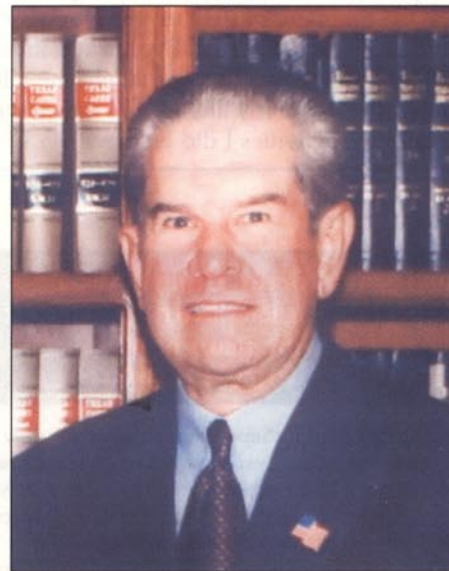


Figure 4.

Mr. Gilmore today.



including ophthalmologists, ENTs, and family physicians. In the case of PRP, the health care provider should stress moisturizing at least four times a day as well as providing internal medication as required.

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

The first dermatologist was treating me for erythrodermic psoriasis. He prescribed very powerful drugs including cyclosporine and Tegison®. He also told me that this flare-up would only last about 4 months. The second dermatologist took me off those two drugs and prescribed methotrexate, then Imuran®. None of these improved my condition. The final drug prescribed was Soriatane®. I took it for 21 months and I believe this helped me. I was emotionally drained when the dermatologist said that PRP would last between 2 and 3 years, but I put myself in

a frame of mind to take it 1 day at a time. I had PRP for 33 months and still experience some residual effects.

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

PRP is a disease that is not fatal and generally has a duration of 2 to 3 years. We have had some people on our Internet PRP Support Group who have had it for longer periods. PRP is a disease that society is not really concerned about; neither are physicians or their research counterparts. My immediate family, relatives, and friends were very much concerned about me, but not the disease, and this is probably the same if a person has a fatal disease. I feel that generally, society does not care about any disease unless they or their loved ones have it themselves. Even then, very few will investigate the causes and treatments.

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

I was a member of the on-line PRP Support Group (www.prp-support.org) for about 6 years. I participated while I had PRP and continued when my symptoms were under control. I listened to the newly diagnosed questions/problems and knew exactly what they were going through. Some individuals took it worse than others. I was very truthful about the average duration of the disease, that there are no miracle drugs, diets, etc., that will expedite wellness, and to take this debilitating disease 1 day at a time. In the meantime, I emphasized that the PRP Support Group and I will help you get through this disease.

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

I have not had any diseases as debilitating as PRP and I am a 4-year survivor of cancer. I had no pain with cancer and the treatments lasted a few months with 2 more years of medication. With PRP, it was an external thing and debilitating for 3 years. I felt badly physically and mentally. It was visible to me and everyone, and my skin still has the remnants of PRP as a daily reminder. I'm more conscious of my skin and I've turned into a sunscreen freak and advocate. PRP has taught me a lesson I will remember the rest of my life. At 71, I now travel, play golf, and do all the activities I did before PRP. 