

More Than a Rash: Skin Disease and Quality of Life

The editors of *AFP* welcome submissions for Close-ups. Guidelines for contributing to this feature can be found in the Authors' Guide at <http://www.aafp.org/afp/authors>.

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A collection of Close-ups published in *AFP* is available at <http://www.aafp.org/afp/closeups>.

One day I felt some bumps on my scalp. I thought I must have hit my head on one of the cabinets, but they didn't go away. By the time I had my appointment with a dermatologist, other symptoms had developed: I had red patches on my extremities, my hands and feet were swollen, my nails had thickened and become discolored, and the skin on my soles was also discolored. The dermatologist looked me over and promptly asked if he could call in the residents. He wanted to know if he could take pictures, so intrigued was he by my skin findings. A few weeks later, biopsy confirmed the diagnosis of pityriasis rubra pilaris (PRP). I had never heard of this condition—it is quite rare—so I had to learn about it.



Skin diseases can have a huge impact on a patient's life. In my case, my skin was constantly red, dry, and scaly. I shed big clouds of scale. My skin fissured, exposing the underlying flesh. I had to buy different shoes for my swollen feet, oil my skin constantly, and worry about sun exposure. My social life was affected, too—I felt the need to explain to everyone I met that I had a rare and noncontagious skin disorder. For other affected individuals, PRP can be much worse because it can cover the entire skin.

Even though PRP manifests in highly individual ways, the most common type often has a predictable duration of three to five years. I have had the disease for more than a year. It has left my arms and legs, and now has become itchy. Because the disease may have a waxing and waning course, I don't know whether this milder period is temporary or a sign of remission. Having a chronic disease has definitely made me more compassionate toward others who live with more serious and debilitating illnesses.—R.S.

COMMENTARY

PRP may be underdiagnosed because it has many mimics, the most important of which is psoriasis. The cause is unknown, but genetic and autoimmune components are likely. Although PRP is self-limited in many cases, the disease is highly variable and impairs quality of life. R.S. approached me about treatment. Should he try acitretin (Soriatane), a systemic retinoid that may hasten clearance? R.S. is a 62-year-old long-distance runner, so I was concerned about fatigue as one of many adverse effects of oral retinoids. He had also been self-insured, so a course of treatment would have cost several thousand dollars. Even with the Affordable Care Act, these expensive medications would not have been covered. Our decision to let the disease run its course has so far been vindicated by noticeable improvements in the past several months.

CAROLINE WELLBERY, MD

RESOURCES

For patients

Healthline

<http://www.healthline.com/health/pityriasis-rubra-pilaris>

National Institutes of Health Genetic and Rare Diseases Information Center

<http://rarediseases.info.nih.gov/gard/7401/pityriasis-rubra-pilaris/resources/1>

PRP Support Group

<http://www.prp-support.org>

For physicians

Eastham AB, Femia AN, Qureshi A, Vleugels RA. Treatment options for pityriasis rubra pilaris including biologic agents: a retrospective analysis from an academic medical center. *JAMA Dermatol*. 2014;150(1):92-94. ■