Skin Wars

In 2014, I seemed to have won an insidious lottery: contracting a rare skin disease that one in 400,000 people get.

It all started with the emergence of a red flaking patch on my right temple. Upon advice of my wife, I emailed an image to Dr. K., and he surmised from the image that it looked as a "likely 'actinic keratoses.' Not serious and can wait till your appointment."

But my skin condition rapidly deteriorated. After meeting with my primary care physician, I contacted Dr. K.'s office again, writing, "I know that the images I have previously sent you seemed not to warrant an earlier visit, but after obtaining my Primary Care Provider's (PCPs) input, I ask whether there might be any time available in next few days. I believe she is also going to write you with her perspective. She seems to believe [as a non-dermatologist] that it is not psoriasis, but a viral issue."

I attached two photos, explaining to Dr. K. that I was now covered by this 'creeping crud,' so felt very uncomfortable. My message described what was happening: "I appreciate your thoughts on next steps. The skin rash has now spread across my body and is raw, very itchy, and I cannot sleep. On my hands and feet, it emerged firstly as small blisters, then erupted into dry scabs, then into horrific bleeding cracks."

At my first visit to Dr. K.'s office, his and his resident's non-verbal responses to my condition made me worry. They seemed shocked at my skin condition. It was clear I had a serious and rare condition warranting immediate research and action. Upon the advice of my PCP, I had immediately stopped the prophylactic statin she had recommended (and ironically I had not needed to take). Paralleling my own thinking that there was linkage between this skin disease and the statin, K. intoned: "There's an old saying -- 'Think drug, think drug, think drug.'" On the website PubMed, K. found a few articles on cutaneous drug reactions to statins. If this is the answer, Dr. K. assumed stopping the statin would lead to an improvement, but

he thought it might take a week or so to have an impact. As events unrolled, this was not the case.

Dr. K.'s initial suggested treatment focused on his belief that "time cures all," a position that matched my sensibilities.

Through submitting a skin biopsy to Boston Medical, it was determined I had *Pityriasis rubra pilaris* (PRP), a rare auto-immune disease. In a review of possible pharmaceutical treatments from other PRP cases, certain drugs seemed to help in about fifty percent of the cases, but the side-effects were so frightening to me, I chose not to go the medication route.

Dr. K. was in regular communication with a colleague and friend in India. This doctor's busy university clinic saw many PRP patients annually and had a depth of experience to offer on my condition. He, however, believed in the use of pharmaceuticals for PRP treatment.

I already had a deep-seated aversion to drug therapy, having watched my parents with multiple major health challenges using physician-recommended medicines as the solutions: pills to sleep, pills to wake up; pills to relieve anxiety, pills to "pep you up." I was not comfortable with a this approach as the immediate treatment and believed the statin I had taken may well have precipitated this disease.

So I opted for the time treatment (aka Tincture of Time). Relief came through trial & error experiments with various creams for my cracking skin: for feet and hands; others for keeping my dry skin moist. These creams slowly began to arrest the unending flaking and scratching of itchy skin, and allowed me to get a full night's sleep. I wore Charlie Chapin-like white cotton socks and gloves to bed, with my feet lathered in heel balm.

Trying to Figure It Out

Trying to understand this rare condition, in the first few months I sought out an international online PRP email group serve that provided a sense of comfort that I was not alone. And it offered such curious information! Some people have PRP

one year and others suffer for 20+ years. And it was troubling that there is no known cause and no known cure. The lack of cures was both unsettling and reassuring. When I shared with the groupserve members that I had started ultraviolet light treatment (narrow band UVB), the response was varied. Some readers warned this treatment did not work for them; others wrote UV, statically, rarely helped. I seemed to be an exception[once again].

Advice between members flowed freely, some of which seemed unlike my experience. Mostly the discussion was around offering sympathy for new sufferers. Given there is so little medical research on PRP, people were desperate for any information, for possible cures.

After a few months, I felt I had learned all I could from the site. I had gained a great deal of emotional support from others, and hope I offered valuable inputs to them as well. As others' situations varied widely from mine my offerings were probably marginal in helping in general ways. It seemed primarily a support group, with many "authorities" on what to do. The website was a valuable support for the first few months, just knowing I was not alone.

State of Emotions

The evolution of this disease has been a physical and emotional rollercoaster for me. After a life of good health, I now faced a major disease that had no known cause, no known cure. It might even be twenty years before my body recovers. Fear of years of unending itching and rawness wore on me. My emotional state was raw, and I was depressed. The immediate condition took all my energy, as I was losing skin at an astonishing rate. I joked I lost a pound of skin a week. I slept throughout the day, rarely went outside. The thought of twenty years of this torturous illness made me ponder whether I would have the emotional and physical strength to continue.

I could not have had hope without the help of the quirky, sensitive dermatologist I luckily found. Dr. K. is the kind of professional I would have teach other doctors. He treated me as an individual, a patient with a curious mind. He took time to answer my unending questions and to get to know me. We constantly

communicated over email, sharing articles and blog site comments. Amidst his busy schedule, he found ways to fit me in for a check-up. Most importantly, I found he respected my preference choices, even after my slow progress.

But there was a challenge of trying medical interventions versus just waiting. Dr. K. gently pushed me, after 7 months of relative little progress, about consider trying methotrexate or isotretinoin. However I remained very cautious of another pharmaceutical solution. After seemingly contracting PRP from a drug, I was still committed to my tincture of time regime.

After six months, I discussed with Dr. K. about obtaining a second opinion. He arranged for a dermatologist outside of Boston with a good clinical reputation. That doctor quickly assessed the PRP, and then recommended I go onto some powerful medicines. Nothing new from him.

So I returned to the regime of waiting, twice-daily creams after showers or baths, narrow band UVB treatments every other day, and also getting as much sunshine as I could. I resigned a stressful job and took vacations on the beach in Florida and Virginia. After 13 months, I have reached some form of stability with this unpleasant malady. I saw an end of my hand and foot cracking and bleeding; an end to the major itching and skin flaking. I can finally sleep through the night. There are small eruptions occurring every few weeks, but they do disappear after time. My UV treatment, twice-daily showers and creams continues, and will do so until it seems either the treatment is causing harm or the PRP disappears.

I remain very thankful for Dr. K.'s guidance and friendship. I couldn't have arrived here without him.