

My Personal Journey with Lymphomatoid Papulosis

As shared by Nikki T.

My life has been transformed in many ways since I was diagnosed with Lymphomatoid Papulosis (LyP) over 19 years ago, and the changes have all been positive. These include increased self-confidence, new friendships, and fulfillment from helping others – all due to life’s unexpected twists and turns after acquiring a rare disease.

This progression actually dates back to 1996, when I was 40 and lesions first appeared on my face. One dermatologist thought it might be adult acne, but additional reddish-brown lesions on my limbs, torso and the top of one foot suggested something else was going on. Other dermatologists also were puzzled until one doctor biopsied three areas. A thigh lesion turned out to be LyP.

LyP is a rare, chronic disease that is a benign form of a cutaneous T-cell lymphoma (CTCL). It occurs in roughly one person out of every million. Most family doctors and even skin specialists are unfamiliar with LyP, which in my case was, at various times, diagnosed as contact dermatitis, psoriasis, eczema, bug bites and a food or bleach allergy. I know of patients who went decades before a correct diagnosis. Mine was the second case seen by my dermatologist in Sonoma County--50 miles north of San Francisco.

TRYING VARIED REGIMENS

My first treatment, a steroid cream, didn’t halt the spread of my “spots.” Because one biopsy revealed a pre-cancerous skin lesion, I decided against an effective phototherapy treatment called PUVA (a combination of an oral medicine named Psoralen and Ultraviolet A light). Instead, my doctor prescribed methotrexate (MTX). Back then, this disease was so obscure that he was unsure about the dosage level and said he checked “an old textbook.”

(As of this writing) I currently take three MTX pills once a week, which limits my lesions to one or two flare-ups a year. A LyP lesion can last three to eight weeks. Mine tend to complete their cycle in two months. I rarely need to see my doctor, but I do have quarterly blood tests to monitor liver function because MTX can damage that organ. I have been fortunate in that LyP hasn’t affected my quality of life. I find it ironic that living with a lymphoma is much easier than managing Type 2 diabetes! My heart goes out to members who have children with this disease, and those who have lesions which result in terrible itching and scarring.

ONLINE SUPPORT NETWORK

At the start of my journey, I was fortunate to be contacted by Judy Jones, founder of the Cutaneous Lymphoma Foundation. She was a reliable information source and became a mentor as I created an online support community in 1998 that soon grew internationally. I served as moderator, with occasional help from Judy. My electronic message list, which had about 760 members, was on Yahoo! Groups. Because of my close ties with the Cutaneous Lymphoma Foundation, in 2006 it developed a LyP Fast Facts pamphlet. That year I also attended an American Academy of Dermatology annual meeting in San Francisco with Judy.

Along with forming the online group, the pamphlet is one of my proudest achievements. More LyP patients are getting correctly diagnosed in a shorter time, thanks partly to information provided for medical professionals on the Foundation’s website and to their education programs for professionals.

WIDER UNDERSTANDING

It’s reassuring to see how much more LyP awareness dermatologists have now than they did in past decades. The reality still is that if a primary care doctor doesn’t refer a patient to a knowledgeable dermatologist, correct diagnosis and proper treatment may end there.

Another ally in advancing research is Dr. Marshall Kadin, whom I met when he lectured in San Francisco in 1999.

Dr. Kadin, chief of dermatology at Roger Williams Medical Center in Providence, Rhode Island, recognized the value of inviting our list members to join the LyP Patient Registry and research database. (In 2012) the registry moved from Harvard University to the University of Arizona, where it's maintained by Dr. Clara Curiel, director of the Pigmented Lesion Clinic and Multidisciplinary Oncology Program.*

This journey of personal development has led me to become an advocate of patients and educator of professionals in the medical field. It's gratifying to know I've helped patients from all over the world. During a 2005 vacation to Great Britain, I met one of our list members at a teahouse in Glasgow, Scotland. We drank coffee and shared experiences of living with the most rare and least understood of the cutaneous lymphomas.

What hasn't changed is the most important advice for anyone with a skin condition that could be a type of cutaneous lymphoma: find a knowledgeable specialist. The Cutaneous Lymphoma Foundation website has links to treatment centers in America, European countries and Australia.

*The registry is now closed and is no longer accepting new patients.