What is Lymphomatoid Papulosis?
Lymphomatoid Papulosis (LyP) is a disease of the immune system that manifests itself in self-healing papules and nodules (“bumps” and “spots”) that come and go spontaneously. LyP can be persistent with recurrent eruptions or it can disappear for weeks or months at a time before reactivating.

Who gets LyP and how common is it?
LyP is a one in a million disease - the overall incidence rate is estimated at only 1.2 to 1.9 cases per 1,000,000 population. The onset of LyP can happen anytime from early childhood to middle age, it affects both sexes equally however it appears to affect caucasion individuals more frequently.

What does it look like?
LyP is characterized by red-brown bumps and spots, that may ulcerate and typically heal with scaling and crusting, and in some instances, scarring. Large plaques or nodules may occur but these are rare. Lesions usually heal over 2-3 weeks but may take as long as 8 weeks. The number of lesions can vary from each eruption and can vary in size and severity with each onset. Lesions may be asymptomatic or can be itchy or painful.

Is it contagious or inherited?
LyP is not contagious. There is no supportive research indicating that this is a genetic or hereditary disease.

What causes LyP?
Although there is continuing research, at this time, no single factor has been proven to cause this disease.

What is the progression of the disease?
In up to 90% of cases, LyP is a persistent or self-limited disease with no associations with other immune system diseases and does not affect the overall health of the patient. In up to 10% of LyP cases, there is an association with lymphomas, cutaneous T-cell lymphoma (mycosis fungoides (MF)), anaplastic large cell lymphoma, or Hodgkins lymphoma. In patients with lymphomas, LyP may develop before, after or at the same time the lymphoma is diagnosed. Some experts consider LyP to be a low grade, self-limited form of skin lymphoma.

Is there a cure for LyP?
There is no known cure for LyP, however, there are therapies that are active in treating lesions. Some cases resolve spontaneously.

How is LyP diagnosed?
LyP is diagnosed by a skin biopsy. The interpretation of the skin biopsy can be difficult and is best done by an experienced dermatopathologist. Patients who are diagnosed with LyP may expect additional studies such as skin biopsies, blood tests, X-rays and scans to detect any associated lymphomas.

What are the treatments for LyP?
Treatment depends upon the severity of the disease. In mild cases, with few lesions, a topical steroid cream may be used. Steroid creams do not prevent the development of new lesions but may be helpful in reducing the lesion symptoms. For widespread disease with many lesions, PUVA phototherapy, oral retinoids and low doses of metotrexate (MTX) can be effective. In patients with LyP-associated lymphomas, treatment of the lymphoma will also clear the LyP in most cases.

Is LyP a CTCL?
CTCL is the acronym for cutaneous T-cell lymphoma. It is a general term for several lymphomas of skin. Most experts classify LyP as pre-CTCL and some classify it as a low-grade form of CTCL. The American Cancer Society does not classify LyP as a form of cancer, but it has been acknowledged as such in Europe. In 1997, the European Organization for Research and Treatment of Cancer (EORTC) formally classified LyP as a form of CTCL.

Where can I go for support?
Join the LyP online Support Group by going to http://health.groups.yahoo.com/group/LyPsupport/. If you have any questions, contact the group moderator, Nikki Thomason at nikkithom@aol.com or info@clfoundation.org.
My life has been transformed in many ways since I was diagnosed with Lymphomatoid Papulosis (LyP) over 14 years ago, and the changes have all been positive. They include new skills, global contacts and fulfillment from helping others – all related to my condition and how I’ve responded.

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.

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 dermatologist prescribed methotrexate (MTX). So obscure was LyP at the time, he had to check “an old textbook” for the dosage level.

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 dermatologist, but I do have quarterly blood tests to monitor liver function because MTX can damage that organ.

LyP hasn’t affected my quality of life, which includes weight training and foreign travel. It seems ironic that living with a lymphoma is much easier than managing Type 2 diabetes. My philosophy is that you learn to roll with it.

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 serve as moderator, with occasional help from Judy. My electronic message list, which has about 760 members, is on Yahoo! Groups. (A signup address is provided in “How to get involved”.)

Along with forming the online group, my involvement in creating this LyP fast facts 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 educational programs for professionals.

Wider Understanding
It’s reassuring to see that dermatologists are now much more aware of LyP than in past decades. However, reality still is if a primary care doctor doesn’t refer a patient to a knowledgeable dermatologist, correct diagnosis and proper treatment may end there.

An ally in advancing research is Dr. Marshall Kadin, whom I met when he lectured in San Francisco in 1999. Dr. Kadin is the chief of dermatology at Roger Williams Medical Center in Providence, RI. He recognized the value of including our list members in the LyP Patient Registry and research database. The registry has since 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 medical professionals. It’s gratifying to know I’ve helped patients from all over the world.

What hasn’t changed is the most important advice for anyone with a skin condition that could be a type of CTCL - find a knowledgeable specialist. The Cutaneous Lymphoma Foundation’s website has links to treatment centers in six American regions, 11 European countries and Melbourne, Australia.

How to get involved
• Support group: Join the online forum by sending email to LyPSupport-subscribe@yahoogroups.com. Moderator Nikki Thomason welcomes questions at nikkithom@aol.com.

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