

CTCL-MF Fast Facts



**CUTANEOUS
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What is CTCL?

CTCL is the acronym for cutaneous T-cell lymphoma. It is a general term for many lymphomas of the skin including mycosis fungoides, Sézary syndrome, lymphomatoid papulosis, cutaneous anaplastic large cell lymphoma, adult T-cell leukemia/lymphoma, peripheral T-cell lymphoma, lymphomatoid granulomatosis, granulomatous slack skin disease, and pagetoid reticulosis to name a few. All cases of mycosis fungoides are CTCL, but not all CTCLs are mycosis fungoides.

What is mycosis fungoides?

Mycosis fungoides (MF) is an old term for the most common type of CTCL. It is a low-grade lymphoma that primarily affects the skin. Generally it has a slow course and often remains confined to the skin. Over time, in about 10% of the cases, it can progress to the lymph nodes and internal organs.

What is Sézary syndrome?

Sézary syndrome (SS) is the leukemic variant of CTCL. Patients usually present with SS, but patients with early stage mycosis fungoides rarely develop SS. The presenting features of SS include widespread redness and scaling of the skin (erythroderma), often with severe itching. Lymph nodes are enlarged and the malignant T-cells found in the skin are also found circulating in the bloodstream.



Who gets it and how common is CTCL-MF?

There is a greater frequency among men than women and it is more common after the age of 50. There are approximately 16,000 to 20,000 cases across the United States and approximately 3,000 cases across Canada. Due to the difficulty of diagnosing the disease in its early stages and the lack of an accurate reporting system, these numbers are estimates.

What does CTCL-MF look like?


One of the problems in describing this disease is that it doesn't look the same for all patients. Patches, plaques and tumors are the clinical names of the different presentations. Patches are usually flat, possibly scaly and look like a "rash." CTCL-MF patches are often mistaken for eczema, psoriasis or "non-specific" dermatitis until an exact diagnosis of CTCL-MF is made. Plaques are thicker, raised lesions. Tumors are raised "bumps" which may or may not ulcerate. A common characteristic is itching, although some patients do not experience itching. It is possible to have one or all three of these types of lesions. Some people have had the disease for many years and have only dealt with one presentation.

What is the progression of the disease?

The course of CTCL-MF is unpredictable. Some patients will progress, slowly, rapidly, or not at all. Most patients will only experience skin symptoms without serious complications. About 10% will experience progressive disease with lymph node and/or internal involvement with serious complications. Many patients live normal lives while they treat their disease and some are able to remain in remission for long periods of time.

How is CTCL-MF diagnosed and what kinds of tests should I expect?

CTCL-MF is difficult to diagnose in early stages, as the symptoms and skin biopsy findings are similar to those of other skin conditions. CTCL-MF is frequently misdiagnosed as other skin conditions and patients may go for years before a definitive diagnosis is established. Both the clinical picture (based on both history and examination) and the skin biopsy findings are essential for diagnosis. Your physician will examine your lymph nodes and order various blood tests including a test for Sézary cells in the blood. Other screening tests such as a chest x-ray or CT scan may be indicated, depending on the patient's history.



Is there a cure for CTCL?

We can't definitively say there is no known cure for CTCL; however, it is important to consider the definition of cure. Some patients can be put into long-term remission (many years) with treatment, which may be considered a cure. The most recent research has indicated that patients diagnosed with early stage CTCL-MF (which is 70-80% of patients diagnosed) will live a normal life expectancy. It is also important to remember that statistics deal with groups of people, not individuals. In the last few years there has been much more research, better treatment options and more collaboration among physicians, all contributing to better care for CTCL patients.

What causes CTCL-MF?

Although there is continuing research, at this time, no single factor has been proven to cause this disease. There is no supportive research indicating that this is a genetic or hereditary disease. Studies have failed to show connections between chemical exposure, environment, pesticides, radiation, allergies and occupations. Exposure to Agent Orange may be a risk factor for developing CTCL-MF for veterans of the Vietnam War, but no direct cause-effect relationship has been established.

Is CTCL contagious?

CTCL is not contagious. It is not an infection and there are no infectious agents known to cause the disease. There has been research investigating the role of viruses, but the results are inconclusive.

What kind of treatment can I expect?

This is an issue that is specific to each individual depending on the symptoms and stage of the disease. Treatments are either directed at the skin or the entire body (systemic). You should be familiar with different treatment options, so you can discuss them with your physician to see what would be best in your situation. Skin-directed treatments include: ultraviolet light (PUVA, UVB, narrow-band UVB), topical steroids, topical chemotherapies (nitrogen mustard, carmustine), topical retinoids (Targretin[®] gel), local radiation to a single lesions or total skin electron beam (TSEB). Systemic treatments include: oral retinoids (Targretin[®] capsules), photopheresis, fusion proteins (Ontak[®]), interferon, systemic chemotherapy. These treatments may be prescribed alone or in combination, to achieve the best long-term benefit to you.

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Cutaneous Lymphoma Foundation
P.O. Box 374
Birmingham, MI 48012
phone: 248-644-9014
fax: 248-644-9014

email:
info@clfoundation.org

web: www.clfoundation.org