Q: What is cutaneous T cell lymphoma?
A: Cutaneous T cell lymphoma is a rare, slow-growing cancer of the immune system cells. CTCL is a class of non-Hodgkin lymphoma characterized by an overproduction of abnormal white blood cells called T lymphocytes, or T cells. These abnormal T cells cause various lesions to appear on the skin, which may initially appear to be a rash. The lesions eventually form tumors and red patches or raised areas called plaques before spreading to other parts of the body.

Q: Are there different types of CTCL?
A: Yes. CTCL is a general term for many lymphomas of the skin. The most common are mycosis fungoides and Sézary syndrome.

- Mycosis fungoides affects between 16,000-20,000 people in the U.S. In 10 percent of patients, the disease spreads slowly to the blood, lymph nodes or internal organs.

- Sézary syndrome is a more aggressive form of the disease. It accounts for about 5 percent of cases and affects cells in the skin and blood.

You may also hear of CTCL being referred to as any of the following:
- Granulomatous slack skin
- Lymphomatoid papulosis
- Pityriasis lichenoides chronica
- Pityriasis lichenoides et varioliformis acuta
- CD30+ cutaneous T cell lymphoma
- Secondary cutaneous CD30+ large cell lymphoma
- Non-mycosis fungoides CD30 – cutaneous large T cell lymphoma
- Pleomorphic T cell lymphoma
- Lennert lymphoma
- Subcutaneous T cell lymphoma
- Angiocentric lymphoma
- Blastic NK cell lymphoma

Q: What are CTCL’s symptoms?
A: Symptoms of CTCL vary. For most people, the first signs are dry skin, itching and a red rash. Some people may see dark patches or the skin may appear red. Red patches or raised areas, called plaques, may be visible. Scaling or flaking on the skin’s surface may also occur.

Many people develop breaks in the skin that may become infected. Some people develop tumors. In more advanced stages, skin tumors may turn into ulcers. Patients may develop enlarged lymph nodes caused by the abnormal T cells that collect in the nodes. In advanced cases, the abnormal T cells may spread to the liver, spleen or intestines.

Q: Do the symptoms of CTCL change over time?
A: Typically symptoms do change over time, but many patients have the same persistent rash or red patches for a number of years. Patients who are diagnosed with advanced disease are more likely to progress to tumor stage or multiple organ involvement than early-stage patients.

Because CTCL can mimic other diseases, diagnosis delays are not uncommon. One long-term study found that the median diagnosis time is 4.2 years.

CTCL is unpredictable. In most patients, symptoms are limited to the skin and there is no progression to multiple organ involvement. Many people with CTCL live normal lives and remain disease-free for long periods of time.
Cutaneous T cell lymphoma

**Q: Who develops CTCL?**
A: Each year, approximately 1,500 people in the U.S. are diagnosed with CTCL. The average age at diagnosis is 55, and men are twice as likely as women to develop the disease.

**Q: How is CTCL treated?**
A: There are two main categories of CTCL treatment: topical and systemic.

**Topical therapies include:**
- Ultraviolet phototherapy – A type of light is delivered to the skin to improve symptoms. This therapy can be administered either in a clinic or at home using a home light unit.
- Steroids – Topical steroids are often the first-line treatments for early-stage rash.
- Nitrogen mustard treatments
- Topical rexinoids – A gel-based medicine is applied to the affected skin to improve symptoms and reduce disease activity.

**Systemic therapies include:**
- Oral capsules – Related to vitamin A, these capsules are recommended for the treatment of skin problems in patients with CTCL who have not favorably responded to at least one prior systemic therapy.
- Extracorporeal photopheresis with UVADEX® Sterile Solution – Blood is removed from the body and treated with UVADEX and ultraviolet A light. The blood is then returned to the body.
- ZOLINZA® – This new drug is taken by mouth and is recommended for the treatment of skin problems in patients who have progressive, persistent or recurrent disease on or following two systemic therapies.
- ISTODAX® – This new drug is given intravenously and is recommended for patients who have received at least one prior therapy.

**Q: What are the different stages of CTCL?**
A: The stages range from IA to IVB:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>Less than 10 percent of the skin is covered with patches and/or plaques.</td>
</tr>
<tr>
<td>IB</td>
<td>10 percent or more of the skin is covered with patches and/or plaques.</td>
</tr>
<tr>
<td>IIA</td>
<td>Any amount of skin is covered with patches and/or plaques.</td>
</tr>
<tr>
<td>IIB</td>
<td>One or more tumors are present on the skin</td>
</tr>
<tr>
<td>III</td>
<td>Nearly all skin is reddened and may have patches, plaques or tumors.</td>
</tr>
<tr>
<td>IVA</td>
<td>Nearly all skin is reddened and may have patches, plaques or tumors.</td>
</tr>
<tr>
<td>IVB</td>
<td>Nearly all skin is reddened and may have patches, plaques or tumors.</td>
</tr>
</tbody>
</table>

For patient appointments
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