



Your  
**CTCL Treatment  
Guide**

# Understanding CTCL

Cutaneous T-cell lymphoma (CTCL) is an uncommon form of cancer.

CTCL is a type of cancer that affects certain kinds of white blood cells, called *T-lymphocytes*.

CTCL is in the lymphoma family. There are many forms of CTCL. CTCL involves the skin. It also can involve the blood, the lymph nodes, and other internal organs.

**Mycosis fungoides** (my-KOE-sis fung-GOY-deez) and **Sézary** (SAY-zah-ree) **syndrome** are the 2 main types.

- **Mycosis fungoides** mostly affects the skin. It can spread to the blood, lymph nodes, and other internal organs in about 1 of 10 people.
- In **Sézary syndrome**, cancerous T-lymphocytes are found in both the skin and the blood.

## Some facts about CTCL

The symptoms of CTCL vary from person to person.

- Some people may have only mild symptoms, such as a rash.
- In others, the symptoms may be more severe. The skin may become red and scaly all over and may become hot, sore, and itchy. Tumors also may form.

The spread or progression of CTCL is not predictable. In most people with CTCL, the disease progresses very slowly or not at all. In a small percentage, CTCL develops quickly, spreading to other organs.

CTCL also is hard to recognize and diagnose. It often is confused with other diseases, such as eczema, psoriasis, or other common, noncancerous skin conditions. One or more skin biopsies (a test that takes a piece of the skin to look at under a microscope) may be needed to diagnose CTCL. Many people with CTCL may go for years without receiving the correct diagnosis and proper treatment.

A number of effective treatments for CTCL are now available. This brochure may help you learn more about treatment options.

# Treating CTCL

Treatment choices are directed at either the skin or the entire body.

Each person's treatment for CTCL varies. Treatment is based on your:

- Type of CTCL
- Extent of disease
- Symptoms
- Age and activity level
- Overall health
- Access to treatment options

Be sure to talk with your doctor about the right treatment for you.

## Treatments for CTCL

### Skin (topical)

- **Medicines you put onto the skin** include topical corticosteroids, chemotherapies, and retinoids (made from vitamin A).
- **Light therapy (phototherapy)** exposes the affected areas of the skin to special ultraviolet (UV) rays.
- **Radiation therapy** uses high-dose x-rays and can include:
  - Local radiation to single areas of the skin
  - Total skin electron beam radiation to the entire body

### Entire body (systemic)

- **Biologic therapies (or immunotherapies)** use the body's own immune system to fight CTCL.
- **Retinoids** are vitamin A-related compounds that are active in treating CTCL.
- **Extracorporeal photopheresis** (EK-stra-core-PORE-ee-uhl FOE-toe-fuh-REE-sis) involves taking blood from a vein and passing it through a machine where it is treated with a drug that makes the white blood cells (particularly T-lymphocytes) more sensitive to UV light. The blood is then exposed to UV light and returned to the body.
- **Chemotherapy** uses a single anticancer drug or a combination of drugs.
- **Bone marrow or stem cell transplantation** is used in certain cases. Bone marrow (or stem cells) is taken from the patient or a donor and stored. When the patient completes intensive chemotherapy, the bone marrow (or the stem cells) is returned to the patient.

# Tracking Your Treatment

Take this tracker to your doctor appointments to talk about how you are responding to treatment.



Whether you are just beginning treatment or have had many years of it, this treatment tracker can help you record your treatment for CTCL. When meeting with your doctor, you may also want to have a list of your questions.

## Treatment tracker

Make copies of this tracker before using it. You may need more space.

Use the tracker to write down:

- Type of treatment
- Dates of treatment
- Response to treatment (*How did it work for you? Did your skin seem better or worse? How long did the treatment work?*)
- The name of and contact information for the doctor and treatment center

| Type of Treatment | Treatment Start Date | Treatment Stop Date | Your Treatment Response | Side Effects | Contact Information                      |
|-------------------|----------------------|---------------------|-------------------------|--------------|------------------------------------------|
|                   |                      |                     |                         |              | Doctor: _____<br>Treatment Center: _____ |
|                   |                      |                     |                         |              | Doctor: _____<br>Treatment Center: _____ |
|                   |                      |                     |                         |              | Doctor: _____<br>Treatment Center: _____ |
|                   |                      |                     |                         |              | Doctor: _____<br>Treatment Center: _____ |
|                   |                      |                     |                         |              | Doctor: _____<br>Treatment Center: _____ |

# Useful Resources

The organizations listed here can help you find the information and support that you need.

Coping with cancer can be stressful. You may have some physical and emotional challenges. Use the information below to learn more about CTCL.

## Education and emotional support

Learning as much as you can about your illness and reaching out to others for support can be helpful.

- **Cutaneous Lymphoma Foundation**  
248-644-9014  
[www.clfoundation.org](http://www.clfoundation.org)
- **American Academy of Dermatology**  
1-866-503-7546  
[www.aad.org](http://www.aad.org)
- **Association of Cancer Online Resources**  
(Patient and caregiver exchange)  
<http://listserv.acor.org/archives/ctcl-mf.html>
- **CancerCare**  
1-800-813-4673  
[www.cancercares.org](http://www.cancercares.org)
- **Lymphoma Research Foundation**  
1-800-500-9976  
[www.lymphoma.org](http://www.lymphoma.org)
- **National Cancer Institute**  
1-800-422-6237  
[www.cancer.gov](http://www.cancer.gov)
- **National Coalition for Cancer Survivorship**  
1-877-622-7937  
[www.canceradvocacy.org](http://www.canceradvocacy.org)
- **The Leukemia & Lymphoma Society**  
1-800-955-4572  
[www.lls.org](http://www.lls.org)

## Physical care

Taking care of your body and getting the treatment you need are important. These organizations may help you find needed resources.

- To find medical centers and doctors who can diagnose and treat CTCL  
**Cutaneous Lymphoma Foundation**  
248-644-9014 [www.clfoundation.org](http://www.clfoundation.org)
- To learn about home healthcare services  
**Visiting Nurse Associations of America**  
617-737-3200 [www.vnaa.org](http://www.vnaa.org)
- To obtain medical supplies, such as sterile gloves or bandages, contact a local medical supply store or ask your doctor for suggestions.

## Insurance and financial help

For many people, dealing with insurance and financial matters adds to the stress of having CTCL. Here are some helpful tips.

- If your doctor determines that you cannot work because of your CTCL, you may be able to receive Social Security Disability benefits or other forms of assistance.  
For information, contact:  
**US Social Security Administration**  
1-800-772-1213 [www.socialsecurity.gov](http://www.socialsecurity.gov)
- For questions about your health insurance coverage, contact the case manager of your insurance company or state department of insurance.
- If you do not have health insurance, contact the social work department at your local hospital.
- Many pharmaceutical companies have programs to provide medicines to people without health insurance.  
For information, contact:  
**Pharmaceutical Research and Manufacturers of America (PhRMA)**  
202-835-3400 [www.phrma.org](http://www.phrma.org)

The Cutaneous Lymphoma Foundation website lists a number of organizations that provide financial and other forms of help to people with CTCL. For information, contact:

**Cutaneous Lymphoma Foundation**  
248-644-9014 [www.clfoundation.org](http://www.clfoundation.org)

The development of this brochure has been made possible by an educational grant from Merck & Co., Inc.



2006 Printed in USA Minimum 10% Recycled Paper ♻️