

A Patient's Guide to Understanding Cutaneous Lymphoma



A comprehensive guide for patients, caregivers and others affected by cutaneous lymphoma



CUTANEOUS
LYMPHOMA
FOUNDATION



WELCOME!

If you or someone close to you has been given a diagnosis of cutaneous lymphoma, you probably have many questions and concerns. Living with cutaneous lymphoma and the many changes that this diagnosis brings to your life can leave you feeling overwhelmed, confused and lonely. You may not even be sure about what kinds of questions to ask.

This guide was created so you can find valuable information to help you understand the disease, learn about available treatments and how to find specialists, access support, and ways to live the best life you can with cutaneous lymphoma.

The Cutaneous Lymphoma Foundation is dedicated to providing patients, caregivers and loved ones with programs and services designed to help, support and provide hope to people who are given a diagnosis of cutaneous lymphoma.

We are here for you.

You are not alone.

You are part of a knowledgeable, caring, resourceful, and compassionate community, and we're here to help you.

Get in touch anytime. We hope to hear from you or meet you in person at one of our patient events.

We wish you all the best in your journey.

The Staff and Board of Directors of the Cutaneous Lymphoma Foundation

A Patient's Guide to Understanding Cutaneous Lymphoma

This guide is an educational resource published by the Cutaneous Lymphoma Foundation providing general information on cutaneous lymphoma. Publication of this information is not intended to take the place of medical care or the advice of your physician(s). Patients are strongly encouraged to talk to their physician(s) for complete information on how their disease should be diagnosed, treated and followed. Before starting treatment, patients should discuss the potential benefits and side effects of therapy.



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PART 1: LEARNING THE BASICS

Chapter 1

Overview of Lymphomas

You've been diagnosed with cutaneous lymphoma – the first thing you may ask is: What does that mean and how might it affect you?

The easiest way to face any diagnosis is to start to understand it – by breaking down the information into manageable pieces. First, let's look at what lymphoma is in general.

Lymphoma is a cancer of a family of white blood cells called lymphocytes. When an infection invades the body, lymphocytes are the cells responsible for recognizing the specific germs responsible for the infection, clearing them, and providing long-term immunity against them. Because lymphocytes travel, reside, and work within the lymphatic system (page 2, figure 1), the lymph nodes swell and grow tender, one sign that an infection has settled in.

There are two types of lymphocytes: B-cells and T-cells. Both work toward similar goals: they identify and fight infections or abnormal cells. B-cells work mostly indirectly: they produce antibody proteins that attach to abnormal cells or infectious agents and alert the immune system to get working. T-cells find the germs, help B-cells make the antibodies, do some direct destroying, and turn on and off the immune response.

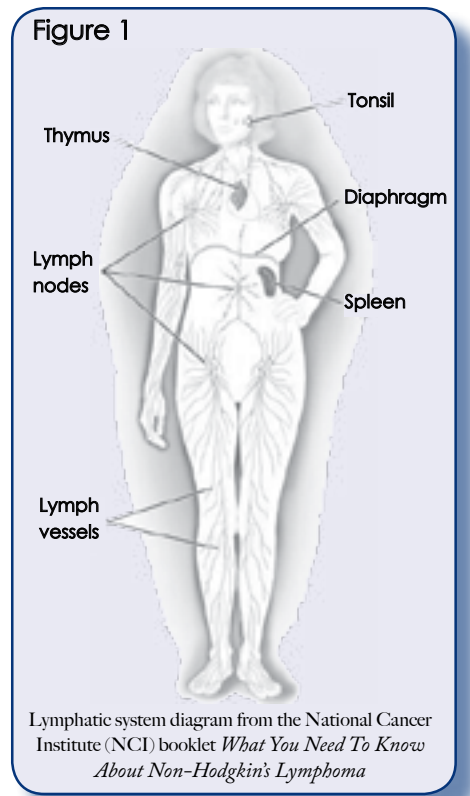
A diagnosis of lymphoma means that one or more lymphocytes, (B-cell or T-cell) have mutated and are multiplying uncontrollably. This is the hallmark of cancer. Naming a specific cancer is based on the type of cells that are involved and from where it starts, not from where it may travel to. For example, if a patient has breast cancer and it migrates to a lymph node or to the bone, it's still breast cancer, not lymphoma or bone cancer. Like all

cancers, lymphomas are now named for the specific type of cells which make them. Thus we have B-cell lymphomas and T-cell lymphomas. This was not always true, however.

Historically, the only diagnostic tool the doctors had was the microscope. Not much was known about B-cells and T-cells and only two kinds of lymphoma were recognized: Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL). HL was the first lymphoma to be identified, and all others were called NHL by exclusion. With the progress in genetics, molecular biology, and immunology, we have learned that the two old classifications actually comprise more than 67 subtypes of lymphoma – six primary types of HL and as many as 61 types of NHL. Now that each type of NHL can be specifically recognized, the distinction between HL and NHL is much less important. All types of cutaneous lymphoma, B-cell and T-cell, belong to the NHL family, of which they represent a very distinct subset.

If one considers all NHLs, B-cell NHLs are far more common than T-cell NHLs: 85% versus 15%. The reason for this is not known. However, if we look only at cutaneous lymphomas, the opposite is true: B-cell lymphomas are far less common than T-cell lymphomas (20-25% versus 75-80%). This suggests that the development of cutaneous lymphomas is distinct from that of other lymphomas.

Because the lymphatic system is connected and works together with the blood and the bone marrow systems, lymphomas are considered blood cancers, like leukemia and myeloma. Lymphoma is the most common



blood cancer in the United States and the third most common childhood cancer. The disease is more common in men than in women, with no scientifically identifiable risk factors or causes. Most cases of NHL are found in adults. The average age of diagnosis is in the early-to-mid 60s.

Many lymphomas are potentially curable – meaning you can rid yourself of the disease forever, not just put it into remission. This may require very strong treatments, though, especially in the case of an aggressive form. Physicians think about lymphoma in terms of its behavior – aggressive or indolent. Simply put, aggressive lymphomas grow more quickly. If not treated, the disease can make a person very sick or become life-threatening within months. Most cutaneous lymphomas are indolent (not aggressive and slow growing).

An indolent lymphoma proceeds over years, often does not make people sick and can be treated multiple times. In most cases, these conditions are chronic rather than curable, and physicians look to manage the situation over the course of a person's life. Most skin lymphomas are very good examples of indolent lymphomas.

Chapter 2

Overview of Cutaneous Lymphomas

In Chapter 1 we learned that cutaneous lymphomas are a distinct subset of non-Hodgkin's lymphoma (NHL), and that they can be divided into cutaneous B-cell lymphomas and cutaneous T-cell lymphomas. Unlike most other types of lymphoma, which develop in lymph nodes, people with cutaneous lymphoma have a cancer of lymphocytes that develops primarily in the skin. While the skin is not typically considered a lymphatic organ, it is the largest surface of interaction between the human body and the environment, and as such is a very important battleground for normal immune responses.

Billions of lymphocytes normally travel to the skin and make it their home for variable lengths of times. When one of these lymphocytes mutates and starts growing uncontrollably, people develop cutaneous lymphoma. The course of the disease will vary depending upon the specific type (B-cell or T-cell), the patient conditions and the stage of diagnosis.

This chapter provides an overview of terms and diagnoses that you might encounter. It is important to know and use the most specific name possible for your disease, so that you can understand the proper course of treatment, what to expect, and potential outcomes. Talk with your healthcare provider about your specific case or condition so that you are armed with the most up-to-date and thorough knowledge possible.

Cutaneous T-Cell Lymphoma (CTCL)

CTCL is the acronym for cutaneous T-cell lymphoma, a general term for several types of lymphomas of the skin that derive from T-cells, including mycosis fungoides, Sézary syndrome, primary cutaneous anaplastic large cell lymphoma, lymphomatoid papulosis, granulomatous slack skin disease, pagetoid reticulosis, and subcutaneous panniculitis-like T-cell lymphoma, to name a few. Most CTCLs typically fall into the category of indolent (i.e. chronic) lymphomas – treatable, but not curable and usually not life-threatening.

In CTCL, malignant T-cells travel to the upper layers of the skin, causing a rash, which leads to diagnosis. CTCL is sometimes wrongly referred to

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as a skin cancer because it affects the skin, but this is not a precise use of the term “skin cancer.” Skin cancer is the designation for cancers that develop from other, non-lymphoid cells of the skin, including epidermal cells (which lead to squamous cell carcinoma) and melanocytes or pigment cells (which lead to melanoma).

As a group, CTCL is a relatively rare family of diseases with approximately 3,000 new cases reported in the United States every year. More common among men than women, CTCL occurs more in patients older than 50 years of age than in younger people. It is important to know, too, that CTCL is not contagious. It is not an infection and cannot be passed from person to person.

There is no known cure for CTCL, though some patients enter long-term remission with treatment and live symptom-free for many, many years. The most recent research indicates that patients diagnosed with the early stages of the most common type of CTCL – mycosis fungoides (which makes up about 70% of CTCL) – have a normal life expectancy. With advances in research and new treatment options resulting from physician collaboration and clinical trials, CTCL patients are experiencing better care and an array of effective treatment options that work for them.

Treatments vary from patient to patient, depending on symptoms, stage of disease and personal health profile. Treatments are either directed at the skin (skin-directed therapies) or the entire body (systemic therapies). It is important that patients discuss fully with their physician all the treatment options before deciding on a course of action.

Skin-directed therapies include ultraviolet light (PUVA, UVB, narrow-band UVB), topical steroids, topical chemotherapy (nitrogen mustard, carmustine), topical retinoids, local radiation to single lesions or total skin electron beam (TSEB) radiation. Full-body, or systemic, therapies include oral retinoids, photopheresis, interferon, and systemic chemotherapy. All treatments may be prescribed alone or in combination, with the goal of achieving the best, long-term benefits for the patient.

The two most common types of CTCL are mycosis fungoides (MF) and Sézary syndrome (SS). Together, they make up about three quarters of all CTCL.

Mycosis Fungoides (MF)

Mycosis fungoides is the most common form of CTCL. Because of that, the terms MF and CTCL are often used interchangeably, and sometimes imprecisely. For example, much of the research on MF reported in the medical journals is listed under the name CTCL, even though MF is just one type of CTCL. This can be a source of confusion. All cases of MF are CTCL, but not all CTCL cases are MF. Mycosis fungoides can appear anywhere on the body but tends to affect areas of the skin protected from sun by clothing.

MF is an indolent type of CTCL, follows a slow, chronic course and very often does not spread beyond the skin. Over time, in about 10% of cases, it can progress to lymph nodes and internal organs. Symptoms of MF can include flat, red, scaly patches, thicker raised lesions called plaques, and sometimes large nodules called tumors. The disease can progress over many years, often decades.

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 it is genetic or hereditary. 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 for veterans of the Vietnam War, but no direct cause-effect relationship has been established.

While the number of new cases diagnosed each year is relatively low (about 3,000), it is estimated that, since patients have a very long survival, there may be as many as 30,000 patients living with cutaneous lymphoma in the United States and 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.

One of the challenges in describing this disease is that it doesn't look the same for all patients. Patches, plaques and tumors are the clinical names for different skin manifestations and are generally defined as “lesions.” Patches are usually flat, often scaly and look like a “rash.” Plaques are thicker, raised lesions. MF patches and plaques are often mistaken for eczema, psoriasis or “non-specific” dermatitis until an exact diagnosis is made.

Tumors are raised “bumps” or “nodules” which may or may not ulcerate (open sores). A common characteristic is itching, although not all patients experience this symptom. Most of the time patients present with patches or plaques. Only rarely are the tumors the presenting lesion. While it is possible to have all three of these types of lesions at the same time, most people who have had the disease for many years experienced only one or two types of lesions, generally patches and plaques.

While on average MF is an indolent, chronic disease, the course in *individual patients* is unpredictable. It can be slow, rapid or static. Most patients will only experience skin symptoms without serious complications. About 10% will see the disease progress to lymph nodes or other internal organs with serious complications. Unlike other types of skin cancer, chiefly melanoma, MF almost never progresses to lymph nodes and internal organs without showing very obvious signs of progression in the skin. Many patients live normal lives while treating their disease, some remaining in remission for long periods of time.

MF is very difficult to diagnose in early stages as symptoms and skin biopsy findings are similar to other skin conditions, leading to frequent misdiagnosis. Patients may go on for years before a definitive diagnosis



is established. Both the clinical findings (based on both history and examination) and the skin biopsy findings are essential for diagnosis. Physicians will examine lymph nodes and often order blood tests including a test for Sézary cells in the blood. Other screening tests such as computed tomography (CT) or positron emission tomography (PET) scans may be indicated, depending on the patient's history.

Sézary Syndrome (SS)

Sézary syndrome is a less common but more aggressive type of CTCL that is related to MF but presents with very severe itching, total body redness (erythroderma), intense scaling of the skin and frequent hair loss. Lymph nodes are usually enlarged, and the malignant T-cells found in the skin are also seen circulating in the bloodstream.

SS is the only type of CTCL that always affects the skin and the blood. The skin may be red from head to toe. Tumor cells are found in the blood, and lymph nodes are larger than usual. The skin may be hot, sore, extremely itchy, occasionally flaking and burning. Oozing of clear fluid from the skin is common. Because much heat is lost through the skin, people often feel cold. Symptoms may be accompanied by changes in nails, hair or eyelids.

Approximately 15% of patients with CTCL have SS. This disease usually occurs in adults older than 50 and is found more in men than women.

Both MF and SS are rare cancers requiring a definitive diagnosis in order to proceed with treatments. Like all cancer diagnoses, both are classified according to stage, which defines how advanced the disease is at the time of diagnosis.

Other Types of CTCL

Lymphomatoid Papulosis (LyP) is a disease of the immune system that manifests with self-healing small bumps and spots on the skin that come and go. It can be persistent with frequent, recurring eruptions or it can disappear for an extended period of time before showing up again. Stress is often reported to trigger the breakouts.

LyP belongs to a family of conditions called primary cutaneous CD30-positive lymphoproliferative disorders (pcCD30+LPD). The name lymphoproliferative disorder is used to define a broad range of diseases of the immune system that share a common biology (in this case the presence

of CD30-positive T-cells) and may span from non-malignant, inflammatory or infectious, all the way to full-blown lymphoma. In the family of pcCD30+LPD, LyP is usually classified as non-malignant or as a CTCL precursor, though some experts say it is a very low-grade form of CTCL. This is a one-in-a-million disease. LyP's overall prevalence is only 1.2-1.9 cases per 1 million people. That said, onset can happen at any time in life – from early childhood to middle age, affecting both genders equally. Black-skinned individuals seem less affected than other racial groups.

LyP is characterized by red-brown bumps and spots, which heal on their own by turning scaly or forming a crust. Lesions can be unnoticed or itchy and painful, taking 2-3 weeks to run their course.

This disease is not contagious, and there has been no supporting evidence to indicate that it is genetic-based or hereditary. In fact, scientists have yet to find a single risk factor for LyP.

The good news is that, in more than 90% of cases, LyP is a persistent but limited disease that does not affect a patient's overall health. There is no known cure, but there are many treatments for living with the disease.

At the other end of the spectrum of pcCD30+LPD, anaplastic large cell lymphoma (ALCL) is a true T-cell lymphoma, which comprises about 20% of all CTCL, but only 3% of all non-Hodgkin's lymphomas in adults. The disease is characterized by the large size and misshape of the cells under the microscope and by the uniform expression of a special marker on the lymphoma cells called CD30.

Like MF, primary cutaneous ALCL (pcALCL) is an indolent, slow-growing type of CTCL, with a good prognosis. Because they are part of the same spectrum of diseases, pcALCL and LyP often are found together in the same patient. LyP, unlike pcALCL, almost always shows spontaneous self-healing, and is occasionally a precursor to the development of pcALCL or other lymphomas, most commonly MF.

Characteristic features of pcALCL include single or multiple raised red skin lesions and nodules, which are larger than those seen in LyP, do not go away, may itch, do not typically crust and they have a tendency to ulcerate. These lesions may appear anywhere on the body and grow very slowly, so they may be present for a long time before being diagnosed.

Cutaneous B-Cell Lymphoma (CBCL)

As discussed in Chapter 1, in general, B-cell non-Hodgkin's lymphomas are much more common than T-cell non-Hodgkin's lymphomas (85% versus 15%). However, in the skin, the opposite is true: CTCL makes up about 75-80% of all cutaneous lymphomas, whereas CBCL makes up about 20-25%. CBCLs are B-cell non-Hodgkin's lymphomas which originate in skin-based B-cells. The fact that most skin-resident lymphocytes are T-cells, rather than B-cells, may explain the difference.

Since systemic or nodal B-cell non-Hodgkin's lymphomas can secondarily involve the skin, when a skin biopsy shows B-cell lymphoma it is very important to make sure that the skin is the only organ involved and that there is not a systemic non-Hodgkin's lymphoma. There is no way to tell the difference between a CBCL and a systemic B-cell lymphoma just based on the biopsy. The three primary types of CBCL are primary cutaneous marginal zone B-cell lymphoma (PCMZL); primary cutaneous follicle center lymphoma (PCFCL); and primary cutaneous diffuse large cell lymphoma, leg type (PCLBCL-LT).

PCMZL and PCFCL are slow-growing lymphomas and are classified as indolent. They respond well to mild treatments, though they often recur. Relapses of slow-advancing CBCL are always confined to the skin and rarely life-threatening. Given the slow, non-threatening nature of this type of the disease, some cases may not even warrant treatment.

PCFCL is the most common type of CBCL. It most commonly shows on the head, neck or upper torso. Lesions are pink or red nodules, or slowly-developing tumors. They rarely become open sores or ulcers. Some patients find nodules in many locations on the body, but more often it is a single tumor or small group of nodules.

PCMZL is also a slow-growing B-cell lymphoma which is related to a type of non-Hodgkin's lymphoma known as extranodal lymphoma of mucosa associated lymphoid tissue (MALT) type. This is the second most common form of CBCL. Patients find pink or red papules, nodules or, less frequently, tumors. It can occur anywhere on the skin but tends to show up on arms, legs or torso.

Diffuse large cell lymphoma, leg type, also known as PCLBCL-LT, is a rare and more dangerous type of CBCL that looks much different under

the microscope, and most of the time is found in the lower legs, where it can reach a very significant size. This version of the disease was first recognized as a more aggressive type of CBCL that showed up on the legs of elderly women. Today, experts recognize this type of lymphoma by spotting the unique molecular features that differentiate it from slow-growing versions of CBCL.

While PCLBCL-LT most often shows up on the legs, it can occur anywhere on the skin; other, slower-growing types of CBCL can show up on the legs so it is imperative not to make a rash diagnosis or an assumption just based on where the disease is first noticed. A biopsy is always needed. PCLBCL-LT often grows into large tumors that extend deep into the fat of the body, growing quickly and becoming open sores. Unlike slow-growing types of lymphoma, this one has a high likelihood of spreading outside the skin.

To determine a diagnosis and classification of CBCL, it is important and appropriate to biopsy the affected skin. Once a diagnosis has been made, clinical staging establishes the course of the disease and informs treatment decisions. The prognosis for most cases of CBCL is usually excellent. Studies show a 96% survival rate at 5 years after diagnosis and a 90% survival rate after 10 years.

Prognosis for the more aggressive PCLBCL-LT is much less optimistic with no more than 50% of patients surviving at 5 years. However, while the mortality rate of patients with PCLBCL-LT is much higher than other forms of CBCL, it is important to remember that most diagnoses occur when patients are in their 80s or 90s and survival rates at 5 years include patients who have succumbed to other natural causes.

Staging

Following are stages for mycosis fungoides and Sézary syndrome:

- Stage IA: Less than 10% of the skin is covered in red patches or plaques.
- Stage IB: 10% or more of the skin is covered in patches or plaques.
- Stage IIA: Any amount of the skin surface is covered with patches or plaques and lymph nodes are enlarged and inflamed, but the cancer has not spread to the nodes.
- Stage IIB: One or more tumors are found on the skin, lymph nodes may be enlarged, but cancer has not spread to the nodes.
- Stage III: Nearly all of the skin is reddened and may have patches, plaques or tumors; lymph nodes may be enlarged, but cancer has not spread to them.
- Stage IVA: Most of the skin is reddened and malignant cells are found in the blood; cancer has spread to the lymph nodes.
- Stage IVB: Most of the skin is red, any amount of skin is covered in patches, plaques or tumors, cancer has spread to other organs.

Chapter 3

Signs & Symptoms

*A **sign** is something a healthcare provider (or the patient) detects on physical examination (objective). A **symptom** is something a patient notices and states to their healthcare provider (subjective).*

One of the challenges in definitively diagnosing cutaneous lymphoma is that its signs and symptoms are not the same for all patients. Patches, plaques, and tumors are clinical names for a variety of skin presentations (also known as lesions) that can be clues that lead to diagnosis.

Patches are usually flat, possibly scaly, and look like a rash. Plaques are thicker, raised lesions. Patches and plaques are often mistaken for eczema, psoriasis, or non-specific dermatitis until a definitive diagnosis is made. Tumors are raised “bumps” or “nodules” which may or may not ulcerate. To be called a tumor, generally a nodule has to be at least 1 cm in size, or greater. A common symptom is itching, although some patients do not experience this. It is possible to have one or all three of these types of lesions. Some people have the disease for years and only experience one.

The most common form of cutaneous lymphoma, mycosis fungoides, often presents with an area of red, slightly scaly skin, usually in sun-protected parts of the body, with variable size and shape. Common locations for these symptoms are the buttocks, trunk, upper thighs – all areas that are typically shielded from sun exposure. Patients with cutaneous lymphoma find their outbreaks in sun-protected areas of the skin because the natural UV component of sunlight may have a protective effect against mycosis fungoides. The exact reason, however, is not known.

Approximately 25% of people diagnosed with mycosis fungoides present with plaques, which are raised, elevated skin lesions. In the most advanced stages, symptoms may include round, dome-shaped lumps or bumps that can break down and ulcerate.

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Other forms of cutaneous lymphoma present in varying ways. Sézary syndrome (SS) is one type that can present in generalized redness affecting 80% or more of the skin's surface. Patients with SS tend to experience very intense itching, perhaps the most intense and relentless itching that has ever been described. These patients will also experience a fair amount of scaling, redness and dryness. They often lose large amounts of skin during the night and may find their bed sheets covered with skin flakes in the morning. This variation presents more dramatically than other types of the disease, making it easier to diagnose because the presentation is more unusual. Sézary syndrome patients will likely also feel tired, have enlarged lymph nodes, may run a fever and just generally feel sick.

Many patients find it takes quite a while to get a definitive diagnosis. A patient may see many physicians who may say "You have eczema" or "It's just dry skin." The reality is that the signs and symptoms of this disease are quite similar to other conditions and it is very difficult to pinpoint a firm diagnosis of cutaneous lymphoma without a biopsy.

Taking the step to biopsy the affected skin can often provide answers. It is almost impossible to have cutaneous lymphoma without at least some signs or symptoms. This type of disease rarely is unnoticed. However, the milder symptoms are commonly confused with other conditions. Some patients, when misdiagnosed, try treatments prescribed for other conditions like eczema or allergies. When those do not work, it can be a clue in the puzzle and can help move a patient toward a proper diagnosis or a referral to a specialist.

Common Signs & Symptoms of Mycosis Fungoides

- Patches
- Plaques
- Itching
- Skin ulcers
- Tumors

Common Signs & Symptoms of Sézary Syndrome

- Diffuse scaling skin (erythroderma)
- Thickening of palms and soles (hyperkeratosis)
- Hair thinning
- Eyelid margin thickening (ectropion)
- Itching
- Enlarged lymph nodes

Cutaneous Lymphoma Symptoms Are Variable

Due to the many different types of cutaneous lymphoma, no two people have exactly the same signs and symptoms, and each person's physical findings and symptoms can change over time.

One person may experience only one symptom while another may experience many more. Most of the symptoms of cutaneous lymphoma can be managed very effectively with medication and other health management strategies.

Chapter 4

Getting a Diagnosis

It can be very difficult to make a diagnosis of cutaneous lymphoma, and this is largely because the signs and symptoms very often look like other conditions such as eczema, allergies, or drug reactions.

Diagnosis of the many subtypes of cutaneous lymphomas can vary and sometimes it takes a long time before it is confirmed. Regardless, the process for diagnosis is similar for all types and may include a physical exam and history; blood tests to identify antigens, or markers, on the surface of cells in the blood; and a skin biopsy (removal of a small piece of tissue) for examination under the microscope by a pathologist (a doctor who studies tissue and cells to identify disease). In the presence of more advanced disease, more testing may be done to determine if the cancer has spread. A bone marrow biopsy may occasionally be necessary to verify complete staging of the disease. This is more likely to be needed with cutaneous B-cell lymphomas than cutaneous T-cell lymphomas.

Both cutaneous T-cell lymphoma (CTCL) and cutaneous B-cell lymphoma (CBCL) require equal consideration and physician attention in order to reach a proper diagnosis. A definitive diagnosis will help inform treatment decisions and potentially yield better outcomes over time. One of the key concepts for patients and caregivers to understand is that a clear diagnosis may take time. While a prompt diagnosis should always be the goal, and a late diagnosis always means deferred relief or resolution of symptoms, it is also important to consider that, in many cases of cutaneous lymphoma, how early a diagnosis is made does not have a major impact on response to treatment and survival. The exceptions are Sézary syndrome and primary cutaneous diffuse large cell lymphoma, leg type (PCLBCL-LT) where a prompt diagnosis is very important. The best approach is to collaborate and work with the healthcare team to confirm the disease type.

In milder cases of cutaneous lymphoma, ruling out non-cancerous reactive rashes and lesions resulting from medication, external environmental or drug exposure, or inflammatory conditions of the skin is crucial. From there, physicians and patients can determine the appropriate

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next steps in care and treatment. With a number of different types and subtypes, building a case for diagnosis based on multiple elements is vital. Assessment of a patient's symptoms, coupled with a history of skin lesions and consistent biopsies, are critical components that help build a patient's individual case and accelerate the diagnostic process.

In some cases, test results, including skin biopsies, are not conclusive. When this happens, patients should discuss options with their healthcare provider. Some may receive the recommendation to seek relief from symptoms by starting a non-systemic treatment such as a topical lotion, steroid cream or ointment, or even ultraviolet light therapy. Others may prefer to wait for a recommendation to take additional biopsies of the skin lesion to aim for more conclusive results.

Importance of the Skin Biopsy

A biopsy is a simple outpatient procedure that involves removing a small sample of tissue from the skin for examination. When a biopsy is performed, local anesthetic is given prior to the procedure. Following the procedure, the skin is sewn together with a couple of stitches, leaving a very small, almost invisible scar.

Given the complexity of cutaneous lymphomas, it is important to have the diagnosis confirmed by a dermatopathologist or a hematopathologist – these pathologists are experts in diagnosing lymphomas. The pathologist analyzes biological tissue and reviews all test results. Typically, the presence of an excess of certain kinds of T-lymphocyte cells, arranged in certain patterns within the tissue, indicates a skin lymphoma. A definitive diagnosis cannot be obtained without a biopsy, and multiple biopsies are necessary to confirm the presence of excess T-lymphocyte cells and consistent patterns. The physician and pathologist will need to work together to determine a proper diagnosis.

To conduct an effective, informative biopsy, patients need to be off topical steroids and ultraviolet light treatment regimens for at least a week or two. While these treatments may provide temporary symptom relief, they can also mask potential symptoms of skin lymphomas and thus delay a patient's definitive diagnosis. Consistent biopsies over time are an integral step in obtaining a proper diagnosis.

Why It Takes Time to Get a Diagnosis

Cutaneous T-cell lymphoma is a complex disorder which often takes a significant amount of time to diagnose. Various studies indicate that the average time from first appearance of symptoms to confirmed diagnosis of the disease ranges from two to seven years.

This delay can lead to frustration for both the patient and healthcare providers. There are two main reasons why diagnosis can take time to confirm. The first is that the disease presents differently on the skin. Only after patients do not respond to traditional therapies for less severe conditions do some physicians consider an alternate diagnosis. Also, there is no single test that will be positive for cutaneous lymphoma every time. The most useful test is a skin biopsy because lesions that appear very similar on the skin may look quite different under the microscope. Many patients require multiple biopsies before a satisfying and complete diagnosis is made.

The need for multiple, sequential biopsies can be exasperating and difficult for patients to understand. Some pathologists compare making the diagnosis from a single biopsy to experiencing a party through a keyhole. One glance may tell you what kind of party it is, but you will not get the full picture until you walk through the door.

Mycosis fungoides is difficult to diagnose in early stages as the symptoms and skin biopsy findings are similar to those of other conditions. There are often misdiagnoses for this exact reason and patients need to be persistent. It also may require seeking out a cutaneous lymphoma specialist at a larger health center. These specialists see many patients with cutaneous lymphoma and work with a multidisciplinary team when diagnosing patients.

Common Procedures For Obtaining A Proper Diagnosis

- Physical exam and history
- Blood tests
- Skin biopsies

Chapter 5

Working With Your Healthcare Team

The best way to manage a disease like cutaneous lymphoma is by assembling the right team of physicians and support individuals to guide your treatment course and help you through each stage of the journey.

Members of your healthcare team may include a combination of the following individuals:

- **You** – You will feel better and more in control when you play an active role in your own health care. It is important to become educated about your disease, your diagnosis, and the options available to you.
- **Your Care Partner(s)** – Family members and friends can offer great support and accompany you to treatment appointments or just be there to talk through the various emotions you may experience as you follow the course of your disease.
- **Dermatologist** – A doctor who specializes in diagnosis and treatment of skin diseases. Some dermatologists specialize in treating cutaneous lymphoma.
- **Oncologist** – A doctor who specializes in diagnosing and treating cancer. Some oncologists specialize in cutaneous lymphoma.
- **Radiation Oncologist** – A doctor who specializes in radiation to treat cancer.
- **Nurse Practitioner** – A registered nurse with advanced education and training who can help your doctors manage the disease, symptoms, and side effects.
- **Social Worker/Clinic Coordinator/Patient Navigator** – This person is tasked with looking at logistics and helping patients plan their course of treatments. This is a person who can help guide patients when they face treatment challenges such as having to travel 50-100 miles for light therapy, communicate with insurance companies, etc.
- **Pharmacist** – An expert in medications who understands and can advise on the use and interactions of medications, and help doctors review allergies and drug-drug interactions (which are common).

Please refer to our website for additional and updated information.

www.clfoundation.org

- **Financial Counselor** – This is an individual, often within the doctor's office, who helps empower patients to navigate their insurance policy, plan for additional uncovered treatments and otherwise meet the financial demands of their course of treatment.
- **Psychosocial Therapist** – This person can counsel you through the emotions you have and outcomes of your disease.
- **Spiritual Guide** – Some patients find it comforting to include a spiritual advisor from their faith community in their support team.
- **Nutritionist** – This person is an expert in providing strategies for finding the right foods and nutrients you'll need to sustain you through treatments.
- **Community of Patients** – Individuals diagnosed with any form of a serious disease find comfort in connecting with others who have walked a similar path. Your healthcare provider or your treatment center can connect you with others who have experience with your particular diagnosis. The Cutaneous Lymphoma Foundation is an excellent resource for helping you connect with others. The Foundation website is a good place to start (www.clfoundation.org).

Before selecting individuals to guide you through treatment, educate yourself on the available options and interview potential providers before including them in your team. Keep in mind the following steps as you proceed:

- Gather information to make treatment decisions with your healthcare team.
- Ask questions.
- Tell your healthcare team how you are feeling – physically AND emotionally.
- Learn about treatment choices/options and potential side effects.
- Seek relief from itching or pain.
- Ask others for support.
- Assign important tasks or chores to friends and family when needed.
- Ask care partners to help with insurance matters as they arise.
- Find a reliable partner to drive you to and from treatment.

The importance of creating a multidisciplinary team to support your treatment course is vital. At some treatment centers, multi-modality clinics exist where you will find all of these support individuals under one roof, but in many cases you will have to compile your own team from the available resources in your town or treatment network. Try to find physicians and support individuals who can work well together, especially with regard to reading test results and communicating with ease over the variables of your diagnosis.

When Should You Work With An Oncologist?

Oncologists are cancer specialists who treat cancer with chemotherapy or other systemic therapies, such as immunotherapy, vaccines, and biological drugs. That is why for cancers that require additional treatment modalities, such as surgery or radiation (i.e. breast cancer, colon cancer, or lung cancer), you always need to see a surgeon and a radiation specialist, in addition to the oncologist.

Cutaneous lymphomas are approached in a slightly different way. Since the treatment for cutaneous lymphoma may consist of skin-directed therapies (usually administered by dermatologists) or systemic therapies (usually administered by oncologists), depending on the stage, a step approach has often been adopted.

Early stages have typically been treated with skin-directed therapy by dermatologists, with little oncology input, and advanced stages have typically been treated with systemic therapy by oncologists, with little dermatology input. While this system may superficially appear to be simple and economical in terms of time management, visits, tests, and payments, and has produced acceptable outcomes in many cases, it has the big disadvantage that patients are often lost in the critical transition from one type of therapy to the other.

Furthermore, adequate pre-planning for systemic therapy in a patient beginning to display resistance to skin-directed therapy cannot be accomplished even by most dermatologists. Likewise, optimal skin care, which remains an essential component of each patient's treatment plan, even in advanced stages, is rarely provided by the oncologist alone. This fact results in one of two frequently observed outcomes: 1) the patient has to keep shuttling back and forth between the dermatologist's and the oncologist's office, often with poor or no communication, which defies the

purpose of efficiency and economy; or 2) the patient simply gets inadequate care. Neither outcome is acceptable. Therefore, rather than focusing on the title and specialty of the healthcare provider, you should try to find a physician who has shown expertise, personal interest, dedication, and leadership in the care of patients with cutaneous lymphoma, regardless of his or her specialty. In some cases it will be a dermatologist, in others an oncologist. Once found, that person will be your “captain,” “steward,” and “advocate” and will help coordinate your care with any other relevant specialist. Basic rule: one leader.

The only better alternative to this scenario is the ideal situation of a multidisciplinary clinic, where the entire team of doctors is wholly focused and dedicated to the care of patients with cutaneous lymphoma. Multidisciplinary clinics, by definition, have an oncologist and a dermatologist on site, both in a leading role, in addition to a large number of additional supporting staff. Such clinics, unfortunately, are available only in a small number of selected cancer centers.

Cancer Specialists	What They Do	Types of Sub-Specialists
Dermatologists	Trained to diagnose and treat skin diseases, including cancers of the skin.	Some dermatologists may specialize in treating patients with cutaneous lymphoma.
Medical Oncologists	Trained in internal medicine and in diagnosing and treating cancer with chemotherapy, biological therapy and other treatments. They often manage the patient's course of treatment, especially when the cancer reaches advanced stages. Medical oncologists may offer consultation services to other physicians treating cancer patients or refer patients to other specialists.	Additional subspecialties can be hematology-oncology.
Radiation Oncologists	Radiologists specialize in treating cancer patients using complex radiologic imaging systems to administer various types of radiation treatment. They work closely with surgical and medical oncologists and other physicians such as dermatologists, who treat cancer patients to help coordinate the overall care of patients.	Radiation oncologists may focus on treating specific types of cancer such as lymphoma and may provide specific types of radiation therapy such as electron beam or laser therapy.
Oncology Nurses and Other Healthcare Professionals	These professionals may specialize in working with specific types of cancer and specific treatment modalities such as photopheresis or dermatology.	Registered nurses, clinical nurse specialists, advanced practice nurses, chemotherapy nurses, radiation therapists and oncology social workers.

Chapter 6

What You Should Know Before Starting Treatment

Before you start treatment, it's important to [get informed](#).

The more knowledge you have about what to expect, the more comfortable you will be as you receive treatment. Armed with information, you will be able to better determine, with your physician, treatment team and family members, that all the options have been weighed and assessed accordingly. Know the full extent of what is available to you before making any decisions. While there is no one perfect pill to make things disappear, a combination of treatments, medications and other approaches – along with a heavy dose of patience – will be your personal remedy. Take into consideration your own capabilities, lifestyle and work demands and other daily details before deciding on a treatment course.

Following is information that can be helpful in preparing yourself for specific treatment options:

Preparing the Skin

For most topical treatments, patients may need to clean and prepare their skin. Patients find better penetration through the skin if their skin is well-moisturized beforehand. Bathing or taking a shower so the skin is well-hydrated before applying medication is a good idea. Many patients associate dry skin with their disease; moisturizers work better if the skin is soaked first and then sealed with emollient.

Preparing for PUVA

For patients getting PUVA (psoralen medication + UVA light) treatment, eye care is essential. There exists a theoretical, though minimal, risk of

patients developing cataracts due to exposure to UVA lights. With that in mind, it's a good idea to have an eye exam prior to the start of treatment to determine that your eyes are healthy. Also, make sure you have protective eyewear, UVA-blocking wrap-around sunglasses, to wear during PUVA treatments. These are available at many superstores and also treatment centers that administer phototherapy.

Because you will be sensitive to light after undergoing PUVA, you'll want to schedule your treatment sessions accordingly. Getting PUVA first thing in the morning may not be a wise choice as you'll likely spend the rest of the day going in and out of sunlight. Discuss your specific lifestyle demands and routines with your healthcare provider to determine the best time of day to schedule light treatments.

Also discuss with your healthcare team the potential side effects of this or any treatment (which can include nausea) because certain natural remedies, like ginger products, may aid in alleviating such symptoms. You will want adequate time to stock up on any such remedies so that when the symptoms arise you are prepared.

Preparing for Photopheresis

The better informed a patient is about photopheresis, the better the procedure will go. Certain blood tests are recommended before beginning photopheresis, where the blood is treated with drugs that are later activated with ultraviolet light. Physicians often check a patient's T-cells and blood-clotting to have a baseline before beginning this course of treatment.

Eye care is an issue with photopheresis, so make sure you have your protective eyewear before beginning treatment. Hydration is also important in this course, so patients should make sure to be well-hydrated for several days before each treatment session. The better hydrated a person is, the easier it will be to access veins for treatment. Many doctors recommend that patients tour the photopheresis unit before undergoing treatment and have their veins checked for accessibility.

Because the treatment takes time, bring reading material or movies to watch to make the time go faster. You will likely develop relationships with others in the treatment unit because many people remain on the same schedule and see familiar faces each time.

Relying on Friends and Family

For skin-directed treatments, you won't need a friend or relative to drive you home. However, you may find comfort in the support of someone close to you when you go for phototherapies, topical therapies or radiation therapies.

When it comes to systemic treatments, especially for the first cycle before you know how you will react, it is a good idea to bring someone with you. A caring companion can allay nerves or fears and, in the event that you have an allergic reaction to a treatment and need relief from an agent like Benadryl®, which can be sedating, you will take comfort in the presence of another person who can help you throughout the treatment experience and bring you home.

Even with chemotherapies, most people are not affected immediately upon receiving treatment. Related nausea, vomiting, and other effects take several days to occur, but it is always comforting to have someone at your side so that anxiety doesn't overwhelm you.

Post-Treatment Expectations

Certain classes of medicines are bigger offenders for side effects like fatigue, nausea and other issues. Pace yourself and plan your time wisely. Do not expect to be operating at the top of your game. Make sure to communicate any and all side effects with your healthcare team, as many symptoms are treatable, even nausea and vomiting. Be aware of your resources and take advantage of your team of experts, who can guide you toward maintaining optimal health and energy levels during treatments.

Managing Anxiety

Because some treatment methods can be confining or claustrophobic, you may experience feelings of anxiety before or during treatment. Integrative processes like hypnotherapy can be helpful in maintaining calm and equilibrium as you face such challenges. Complementary care is often helpful in achieving balance for your emotions and your physical symptoms. Consider consulting with a nutritionist, reiki therapist, massage therapist, hypnotherapy expert, acupuncturist, acupressure therapist, yoga teacher, xi gong instructor or others to help you handle stress and maintain a sense of control.

Physical Limitations During Treatment

Many patients experience fatigue or depression during their treatment course. Knowing this is a real possibility helps you prepare for such an outcome by seeking out the help of a therapist to talk with during treatment and altering your schedule to account for reduced energy levels.

Healthcare providers are likely to ask if you have trouble falling asleep, if you have bad dreams and nightmares, and if you're feeling blue or tired. Don't be afraid to seek out anti-depressants to ease such side effects. Some treatment medications can actually induce depression. Integrative modalities and pharmacological solutions are available to help you through.

Pace yourself. Do not overload your schedule with commitments. Try to postpone any non-essential appointments until your treatment course finishes.

Don't Believe Everything You Read

In this information age, many patients read research related to their disease on the Internet before ever meeting with their healthcare team. There is so much information out there, and the Internet does not discern between your particular situation and other conditions. Information can be scary – especially if it is not specifically related to your case. Try to resist the temptation to dig out any and all information online. Educate yourself with the resources your physician recommends and ignore the rest. Hospital-approved patient education materials give you a window into the world of your specific situation, the therapies available to you and approved by your providers, and the outcomes you can anticipate. The Cutaneous Lymphoma Foundation is a very good source of information about treatment options and the latest therapies.

Please refer to our website for additional and updated information about treatment options & treatment centers:

www.clfoundation.org/treatment

Chapter 7 Treatment Options

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Many effective treatment options exist for cutaneous lymphoma. Your healthcare team will determine the best course of treatment for you based on a set of variables:

- Goals of therapy
- Stage of disease
- Prior treatments and the response to those treatments
- Age and activity level
- Costs, coverage, and accessibility
- Other health conditions such as diabetes, heart disease, etc.
- General health concerns and lifestyle considerations

In treating cutaneous lymphomas, unlike most other cancers, physicians often use the same treatment repeatedly, such as light therapy and radiation. What worked once often will work again. Patients with early-stage cutaneous T-cell lymphoma (CTCL) can often achieve long-lasting remissions with skin-directed therapies. In CTCL, since malignant T-cells are thought to spend the majority of their time in the skin and are dependent on the skin for survival, therapies aimed at the skin are likely to be effective for a long time.

Across the United States, there are many cutaneous lymphoma treatment centers. Many patients find they need only to visit their doctor's office for treatment, while others require a local hospital or a specialized cutaneous lymphoma treatment center. It is important during and after treatment to keep a master file of medical records for future reference as needed. Documentation tools are available at Cancer101 (www.cancer101.org) and LIVESTRONG (www.livestrong.org) for capturing the data associated with care and treatment. These are free to patients.

The goal of treatment for cutaneous lymphoma is to clear up all patches, plaques, or tumors; to reduce the number of T-lymphocytes in the blood (for Sézary syndrome); and to relieve symptoms such as pain, itching,

burning, and redness. Additionally, patients tend to handle treatments better when they maintain a healthy diet and exercise regimen and report any new symptoms or changes to their physicians during treatment.

Treatment choices for cutaneous lymphoma are directed at either the skin (topical) or the entire body (systemic). It's important to discuss with your healthcare team the benefits and disadvantages of both before making a decision on your treatment course. There have been very few studies done to compare the effectiveness of one therapy for cutaneous lymphoma with another, so it is an individual matter of trial and error until your healthcare team finds the right combination of treatments for you.

Here are some common treatment options:

- Medications you put on the skin including topical corticosteroids, chemotherapies, and retinoids (made from Vitamin A).
- Light therapy (phototherapy) that exposes affected areas of the skin to special ultraviolet (UV) rays.
- Radiation therapy that uses high-dose X-rays and can include local radiation to localized areas of the skin or total skin electron beam radiation over the entire body. Radiation treatment destroys cancer by focusing high-energy rays on cancer cells. Radiotherapy can be used alone or in combination with other treatments. Side effects may include mild skin changes resembling sunburn or suntan, nausea, vomiting, diarrhea, or fatigue. Most side effects ease a few weeks after treatment finishes.
- Biologic therapies (or immunotherapies) use the body's own immune system to fight cutaneous lymphoma.
- Retinoids are Vitamin-A related compounds that are active in treating cutaneous lymphoma.
- Extracorporeal photopheresis (ECP) involves taking blood from a vein and passing it through a machine, where it is treated with a drug that makes 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. Chemotherapy uses chemicals that interfere with cell division,

damaging proteins or DNA so that cancer cells will die. Chemo treatments target any rapidly-dividing cells (not necessarily just cancer cells), but normal cells usually recover from chemical-induced damage while cancer cells cannot. Chemotherapy is generally used to treat cancer that has become systemic and advanced because the medications travel throughout the entire body. Treatment occurs in cycles so the body has time to heal between doses. Some side effects include hair loss, nausea, fatigue or vomiting. Combination therapies often include multiple types of chemotherapy or chemotherapy combined with other treatments.

- Bone marrow or stem cell transplantation is considered in cases for patients with advanced disease. Allogeneic stem cell transplantation is the recommended transplantation method for advanced cutaneous lymphoma patients. However, most cutaneous lymphoma patients will never need to evaluate this option. Stem cell transplantation refers to a procedure where healthy stem cells are transplanted from one individual to another, or from an individual back to his or herself. Sources of stem cells include bone marrow, peripheral blood or umbilical cord blood. Hematopoietic stem cells can grow into any of the cells found within the bloodstream. They make blood cells and the components that your immune system needs to function. During a transplant, your body is infused with healthy stem cells which then grow and produce all of the different parts of the blood that both your body and your immune system need.

Before you begin a treatment protocol, you will want to learn as much as possible about the course of action that your healthcare team has designed. Write down questions about your illness, treatments, or side effects to discuss with your doctor. Take someone with you when you go for doctor visits – that way, you won't miss important information with an extra set of ears present. You may even want to tape-record your healthcare visits for later review providing you obtain permission from your doctor beforehand.

To help you decide which treatment path is right for you, there are some good questions to ask your healthcare team besides “what are side effects?” and “how well does this treatment work?” See the following page for suggested questions.

Questions To Ask About Treatment

1. How confident are you in my diagnosis of cutaneous lymphoma? The less confident your doctor is in the diagnosis, the less risk you should take with therapies.
2. What type of cutaneous lymphoma do I have? Patients with mycosis fungoides should expect a different menu of treatment options than patients with Sézary syndrome and cutaneous B-cell lymphoma. For example, topical creams are not effective for Sézary syndrome but may be perfect for mycosis fungoides.
3. What stage of cutaneous lymphoma do I have and what is my prognosis? **This question is KEY.** In general, early-stage patients (IA, IB, IIA) should consider topically-applied medications or ultraviolet light therapy over pills and IV medications because they are usually very effective, have fewer side effects, and the prognosis is usually very good. Because more advanced-stage patients (IIB, III, IV) have a worse prognosis, these patients may consider taking more risks with therapy choices.
4. What are the short and long-term side effects? How likely are they? Are they reversible, and how long may they last? These are important questions that are a major factor in many patients' decisions.
5. How inconvenient are the treatment options? (How often? Where? For how long?). Unfortunately, all treatments create at least some inconvenience for patients, but each patient will view the details of their protocol differently as to how it fits into their life.
6. How expensive are the treatment options and how likely is it that my insurance will pay for them? **Don't hesitate to ask this question!** Your clinician may not have an immediate answer, but he or she should help you find one. There's no harm in trying the least expensive option if it is as effective as a more expensive choice.

One way to help you track all the details and information is to create a chart of your options and the factors that are important to you. You'll find a sample worksheet at the end of this chapter to help you keep track of details. Additionally, systems for tracking this information are available from Cancer101 (www.cancer101.org) and LIVESTRONG (www.livestrong.org).

There are many effective therapies available for all types of cutaneous lymphoma. It is not always easy to decide which treatment course is optimal for you. Follow these tips to help in your decision-making process:

- Look for doctors who have treated many cases like yours. Because this is a rare disease, it is impossible for even the best local doctor to be up-to-date on the latest treatment options. Find a specialist.
- Ask questions. It is hard to remember what questions you want to ask when you are in the exam room. Write down questions in advance and after each visit so you don't forget. Take someone with you so you can talk over what the doctor told you.
- Get a second opinion. Many people like to get information from several sources so they feel confident before making treatment decisions and moving forward.
- Take your time. There is a lot to be said for taking time to consider your options and not rush into any decisions. While it is important to start treatment as soon as possible, do not rush to make an immediate decision.
- Make sure your healthcare provider understands you. Share any and all personal details of your lifestyle, schedule, routine, and concerns so that he or she understands where you're coming from and what factors will affect your treatment choices. Talk to your healthcare team about what is important to you. Depending on your situation, one treatment may be better than another. Ask your healthcare provider about all the possible treatment options so you can have thorough information before making a decision.

Understanding Cutaneous Lymphoma Therapies

Treatment for cutaneous lymphoma is very individualized and specific to each person depending on the symptoms and stage of the disease. For many early-stage patients, skin-directed therapies are effective. Cutaneous lymphoma patients with resistant skin disease or blood and internal organ

involvement require systemic therapies. More aggressive therapies become necessary later in the disease, when malignant T-cells depend less on the skin and the disease moves beyond the skin. The therapies most commonly employed in the management of cutaneous lymphomas are described on the pages that follow.

SKIN-DIRECTED THERAPIES

Topical Corticosteroids

These are the cornerstone of treatment for a host of skin conditions. Topical steroids are not cosmetic – they actually kill lymphocytes. These agents possess multiple immune surveillance and anti-inflammatory effects. In early-stage disease, topical corticosteroids can induce and maintain clinical clearing of lesions for extended periods of time. Itching is often markedly improved with the use of these agents. Topical steroids are packaged in a variety of ways including creams, ointments, lotions, solutions and gels. Pulse topical steroids refer to the application of a strong topical steroid (Group I) twice daily for 2 weeks alternating with a lesser mid-potency agent (Group III or IV) applied twice daily for 2 weeks. This pattern is repeated for up to 12 weeks.

Phototherapy

One of the most widely recommended treatments for cutaneous lymphoma is ultraviolet light therapy (phototherapy). Patients with more extensive skin involvement (more than 30% of total body surface) are often prescribed phototherapy when topical treatments might be impractical. Phototherapy is delivered in the form of ultraviolet B (UVB-broad or narrow band) or PUVA (psoralen medication + ultraviolet A).

- UVB refers to a shorter spectrum of ultraviolet light that causes sunburns. In a controlled environment, UVB phototherapy can produce marked improvement in patch and plaque stage lesions as well as control symptoms of itch. This form of UV light treatment does not require the administration of an oral medication. UVB can be delivered in private dermatology practices or hospital settings. Most patients receive 3 treatments per week, increasing length of time from a few seconds to a few minutes. As the disease improves and remission is reached, the frequency of UVB treatments diminishes over time to 1 per week.
- PUVA refers to ultraviolet A (the longer spectrum of ultraviolet

light) plus psoralen, a compound that makes UVA light biologically active in skin cells. PUVA treatment penetrates deeper into the skin and is helpful in managing patients with thicker plaques or who have cutaneous lymphoma involvement at the hair follicle level. Similar to UVB therapy, PUVA is administered in a dermatology practice or hospital setting. Patients take the prescribed psoralen medication 1 hour prior to exposure to UVA light. Protective eyewear is worn for 12-24 hours after treatment ends. Once a patient has achieved clinical improvement with PUVA, a gradual taper in the frequency of treatments takes place with a goal of treatment delivery every 4-8 weeks.

Topical Chemotherapy

Mechlorethamine (Mustargen®), also known as nitrogen mustard, and carmustine (BiCNU®) are cytotoxic (cell-killing) chemotherapeutic agents that are used topically in early-stage cutaneous lymphoma. These drugs have demonstrated very good results when used in patients with limited or extensive skin involvement and recalcitrant disease after other skin-directed therapies have been attempted. A specialty pharmacist, also known as a compounding pharmacist, mixes the nitrogen mustard or carmustine. The chemotherapeutic agent can be mixed in an aqueous, ointment, or gel vehicle. Topical nitrogen mustard is not absorbed systemically, so it does not cause nausea or hair loss.

Bexarotene (Targretin®) Gel

Bexarotene or Targretin® gel is a Vitamin A derived agent that belongs to a larger class of medicines called retinoids. Retinoid X receptors (RXRs) steer abnormal T-cells toward cell death. Targretin® gel is applied as a topical agent in the management of stubborn earlier-stage lesions. During the first few weeks of treatment with this agent, a topical corticosteroid is often used together with Targretin® gel to decrease local site irritation.

Radiation Therapy

Radiation therapy shares a long history in the repertoire of treatments for cutaneous lymphoma, dating back to the early 20th century. In the 1940s, accelerated electrons replaced traditional photon-based radiation. Spot electron beam therapy may be delivered as a localized (“spot”) short course for a limited skin surface area. Typically spot electron beam therapy is delivered anywhere from 2 to 15 treatments.

Total skin electron beam therapy (TSEBT) has undergone many modifications and advances through the years with the goal of delivering the radiation to the target tissue (skin) and minimizing the damage to surrounding tissues. TSEBT is administered in the out-patient hospital setting under the direction of an expert radiation therapist. Typically patients receive TSEBT daily for an approximate 10-week treatment cycle. As a skin-directed therapy, TSEBT is highly effective for patients with extensive skin involvement with plaque or tumor stage lesions.

SYSTEMIC THERAPIES

Extracorporeal Photopheresis (ECP)

Extracorporeal photopheresis (ECP) is an immunotherapy recommended in cutaneous lymphoma patients with an abnormal circulating T-cell population identified in the peripheral blood. During ECP, white blood cells are separated out and exposed (outside the body) to UVA light and then re-infused. It is believed that the UVA-exposed white blood cells produce a vaccine-like effect against malignant T-cells. Other treatments (interferons, Targretin®) are frequently used in concert with ECP therapy.

Nurses administer photopheresis treatments two successive days every 3-4 weeks in outpatient settings. ECP is most often used when there is blood involvement. In ECP, the cells are bathed in psoralen before being exposed to UVA light.

Oral Corticosteroids

Corticosteroids are medications used to treat a variety of skin diseases that may be acute or chronic in nature. These agents share a wide range of applications for a host of immune-mediated diseases. In cutaneous lymphoma, oral corticosteroids may be used to down-regulate inflammatory cells when the skin disease is extensive and symptoms associated are remarkable.

Examples of corticosteroid medications include cortisone, prednisone, and methylprednisolone. Prednisone can be prescribed as a taper whereby the dosage is gradually reduced from 40-60 mg to 5 mg over the course of a few weeks. In other circumstances, low dose prednisone (10-20 mg) may be administered daily on a long-term basis. Some of the commonly encountered side effects with long-term administration include fluid retention, weight gain, increased blood pressure, increased blood sugar,

increased appetite, stomach irritation, mood elevation, sleep disturbance, acne, and delayed wound healing.

Interferons (IFN)

Interferon is a naturally-occurring protein that carries anti-viral, anti-tumor, and immunological properties, and can be manufactured in large amounts for use as a drug. In the management of advanced-stage CTCL, physicians seek immune stimulatory effects. Interferon alfa 2b (Intron A®) and Interferon gamma 1b (Actimmune®) represent two different categories of synthetic interferons used in treating this disease. Interferon is patient-administered by subcutaneous injection 3 days per week. Laboratory tests to monitor complete blood count and liver function are required. Most often interferon is used in combination with other therapeutic modalities such as photopheresis.

Bexarotene (Targretin®) Capsules

Bexarotene or Targretin® is a Vitamin A derived agent that belongs to a larger class of medicines called retinoids. Retinoid X receptors (RXRs) steer abnormal T-cells toward cell death. Oral Targretin® is a systemic agent approved for all stages of cutaneous T-cell lymphoma. Laboratory monitoring (blood tests) of both lipids and thyroid hormone are required during the course of this therapy.

Denileukin Diffitox (Ontak®)

Denileukin Diffitox or Ontak® is an approved drug for the treatment of recalcitrant cutaneous lymphoma. It is a fusion toxin formed by the combination of diphtheria and interleukin-2. Ontak® is selectively cytotoxic to malignant T-cells. Nurses administer Ontak® by intravenous infusion over the course of a 1-1/2 hr. time period. Typically patients receive Ontak® 5 consecutive days (a cycle) every 3 weeks for 6 cycles. Maintenance therapy may be recommended if clinical remission is achieved. At the time of the publication of this guide, the company that makes Ontak® has stopped manufacturing the medication and there is no information as to when production may resume.

Vorinostat (Zolinza®)

Vorinostat or Zolinza® is a histone deacetylase inhibitor (HDAC) oral agent for patients with progressive or persistent manifestations of cutaneous lymphoma. HDAC inhibition allows a cell's DNA to be transcribed so that cancer cells may die off. This medication requires

frequent blood, electrolyte, platelet count and electrocardiogram (EKG) monitoring for the initial weeks of therapy. Zolinza® is used alone or in combination with other therapies.

Romidepsin (Istodax®)

Romidepsin or Istodax® is another histone deacetylase inhibitor (HDAC) agent available for patients with cutaneous lymphoma who have received at least one prior systemic therapy. Istodax® is administered by intravenous infusion over 4 hours every week, for 3 weeks, followed by a rest week. Similar to other HDAC agents, monitoring of blood tests including electrolytes, magnesium and platelets is essential.

Chemotherapy

Chemotherapy administered as single agent or in combination may be used to treat the manifestations of advanced cutaneous lymphoma. Combination or multi-agent chemotherapy is usually reserved for advanced stages of disease. The following single-agent chemotherapy drugs are known to be “gentler,” so they do not cause much hair loss or vomiting. With most of these agents, physicians will monitor blood counts and kidney and liver function.

Methotrexate (Matrex®) is an anti-metabolite agent used for a host of immune-based diseases. It interferes with folic acid metabolism in cancer cells. In cutaneous lymphoma, this is administered in oral form by pill weekly.

Pralatrexate (Foloty®) is used in the treatment of transformed mycosis fungoides and other aggressive non-Hodgkin's lymphomas such as peripheral T-cell lymphoma. It is a folate metabolic inhibitor which targets the same pathway as methotrexate. Patients receiving pralatrexate therapy take a daily dose of folic acid and receive Vitamin B 12 injections every 8 to 12 weeks. It is delivered intravenously every 3 weeks, followed by a rest week.

Alemtuzumab (Campath®) is a monoclonal antibody directed against the CD52 antigen (surface marker) found on both B-lymphocytes and T-lymphocytes. It is typically administered in low-dose form by subcutaneous injection 3 days per week for an 8-12 week course. Patients receiving Campath® are prescribed oral antibiotics and antiviral

medications to protect the immune system while on therapy and for up to 6 months afterwards.

Liposomal Doxorubicin (Doxil®) is a special formulation of doxorubicin, a drug that interferes with DNA activity in cancer cells. The liposome, or microscopic sphere of fat surrounding the doxorubicin, minimizes side effects and improves activity. Doxorubicin is delivered by intravenous infusion every 2-4 weeks. Certain patients will have an evaluation of heart function performed prior to starting therapy.

Gemcitabine (Gemzar®) is a chemotherapy drug that works by interfering with DNA production in cancer cells. It is delivered by intravenous administration usually weekly for 2-3 weeks, with a week of rest before the cycle is repeated.

Multi-Agent Combination Chemotherapy

The use of chemotherapy drug combinations in cutaneous lymphoma should be discouraged because they have never been proven to be more effective than sequential single agents, and they are always much more toxic. Combinations such as CHOP (cyclophosphamide, doxorubicin, vincristine, and prednisone), ESAHP (etoposide, solumedrol, high-dose ara-C, and cisplatin), and GND (gemcitabine, navelbine, and doxil) may be used when no other therapy is available, or in rare circumstances as a way to produce brief responses in preparation for a bone marrow transplant.

Clinical Trials

The best way to identify effective drugs and find new ways to treat cutaneous lymphoma is through ongoing research and testing including clinical trials. Because this disease is less common than other forms of cancer, scientists depend upon willing participants. Clinical trials are crucial in identifying prognostic strategies and determining optimal doses for patients.

If you are interested in participating in a clinical trial, talk to your doctor about which ones may be appropriate and available for you. You can also find information about current and ongoing clinical trials on the Cutaneous Lymphoma Foundation's website (www.clfoundation.org). You can learn more about clinical trials in Chapter 17 of this guide.

TREATMENT TRACKER

You can use this worksheet to keep track of each type of therapy or medications you have received to capture your experience and keep in a binder or electronically. If you are interested in a more formal way to record your treatments along with other information, you may want to order a tool from either **LIVESTRONG** (www.livestrong.org) or **Cancer101** (www.cancer101.org).

Type of Treatment	Treatment Start Date	Treatment Stop Date

Your Treatment Response	Side Effects	Contact Information
		Doctor: _____ Treatment Center: _____
		Doctor: _____ Treatment Center: _____
		Doctor: _____ Treatment Center: _____
		Doctor: _____ Treatment Center: _____
		Doctor: _____ Treatment Center: _____

Cutaneous lymphoma is a rare disease in general. It is even rarer to find it in children. In Europe and the United States, up to 5% of all cases are diagnosed before the age of 20. However, in some parts of the world, such as the Arab populations in the Middle East, children constitute up to 60% of the patients with mycosis fungoides. Prevalence rates differ greatly among geographic regions and populations.

Many researchers believe that mycosis fungoides, in young people in particular, may have a genetic component and may be triggered by environmental factors. In fact, there may be a link between skin type and early incidence of this disease. For example, African Americans are diagnosed with mycosis fungoides before the age of 40 significantly more often than Caucasians.

Despite the infrequent occurrence of this disease in children, the principles of diagnosis remain the same regardless of age. However, there are some special considerations regarding this age group. For example, physicians devote extra attention to determining a course of treatment for younger patients, weighing the benefit of therapy against any potentially long-term complications more prevalent among the pediatric age group than adults. Phototherapy is the preferred treatment for mycosis fungoides, but if a child is very young, they are technically unsuitable for it.

Among children, the distinguishing features of this disease can be misleading, making it ever more difficult to diagnose cutaneous lymphoma in children. Another complicating factor is that the medical community is usually hesitant to perform biopsies on children unless there is absolute indication of the presence of this disease – and biopsy is the best way to firmly diagnose cutaneous lymphoma. For these reasons, diagnosis in children is often delayed much longer than in adults. The prognosis for children is similar to adults.

When children have chronic inflammatory dermatitis, which are ongoing skin conditions that are not classified with a certain diagnosis (an unusual

Please refer to our website for additional and updated information.

www.clfoundation.org

presentation of psoriasis, eczema or atopic dermatitis), physicians must consider the possibility of mycosis fungoides. The challenges of diagnosing and treating such complex and often ambiguous diseases are magnified by parents' concerns, expectations, and a child's own level of understanding.

It has only been in the last several years that investigators have truly begun to understand the characteristics of pediatric presentations of cutaneous lymphoma as more data has become available.

Treatment decisions for pediatric patients are difficult to make because younger patients are more sensitive to the adverse effects of certain therapies. Of particular concern, given their young age, pediatric patients have more time to develop and experience the long-term adverse effects of anti-cancer therapies. When treated with oral/topical psoralen plus ultraviolet A (PUVA) or narrowband UVB phototherapy, local radiation therapy, or total skin electron beam therapy, younger patients are inherently subject to greater risk for developing skin cancers because they have a longer expected lifetime ahead of them.

Similarly, pediatric patients in need of systemic chemotherapy may develop leukemia later on in life, and patients taking retinoids such as isotretinoin (Accutane®) are at risk of premature stunting of bone growth. Topical corticosteroids and nitrogen mustard may be among the safer treatments for early-stage disease with less cancer risk. In the end, proper treatment for pediatric cutaneous lymphoma is individualized to the unique occurrence and needs of each patient.

Although rare, some younger adults are diagnosed with cutaneous lymphoma. For patients newly-married or in the dating scene, this can be a devastating diagnosis. The hardest part, say some patients, is the physical presentation of the disease – especially if you're in an active workplace or dating. A facial rash or other obvious outbreak can make you self-conscious. "You feel like you're a broken individual," one patient said, "like you're not whole anymore."

Treat your diagnosis like any other serious medical diagnosis – this is cancer, after all, and if you put it in those terms to colleagues and friends, they may be more understanding. The good news is that, with appropriate, effective treatments in the beginning, there is the hope that you'll experience a long remission. Many patients do.

It helps to connect with others in your situation. Reach out to the Cutaneous Lymphoma Foundation to find others in your age range who are experiencing similar symptoms and situations. Connecting with others who have experienced what you're going through can make the journey a lot easier.

Treatment paths for cutaneous lymphoma vary from creams and ointments to prescriptions, procedures and intravenous or light therapies. In the United States, there are many qualified centers where patients with cutaneous lymphoma can be treated, especially during the early stage of the disease. For patients whose disease has advanced, treatment may fall under the realm of an oncologist, cancer center or chemotherapy clinic.

If you live in a rural area or small town, you may find that it is difficult, if not impossible, to obtain certain treatments. You may need to travel to have your treatments, and there may be costs involved with that. If the costs become too prohibitive, some clinics have individuals appointed to guide patients through the process of finding, affording and implementing the proper treatments. Most major medical centers have provisions for helping people stay for lengths of time to fulfill their treatments.

The Cutaneous Lymphoma Foundation, physicians, nurses, pharmacists and other healthcare providers can be powerful resources full of information and ideas to help you get what you need. There are organizations that specialize in assisting patients with cancer through their challenges with obtaining medications along with financial, employment, insurance and other issues.

You can find many helpful organizations in the RESOURCES section of this guide. Check the Cutaneous Lymphoma Foundation website for up-to-date resources (www.clfoundation.org).

Please refer to our website for additional and updated information.

www.clfoundation.org

Chapter 10

Coping With Treatment Side Effects

Treatments are intended to relieve the symptoms of your disease, but it is often the side effects from such treatments that create discomfort and make daily life challenging. Let your doctor know if you experience any of these side effects from treatments:

- Skin irritation and inflammation
- Redness, rash, and itching
- Heat, tenderness, or burning sensation (like a sunburn)
- Fatigue or depression
- Flu-like symptoms

Many oral medications and IV chemotherapy can also cause change in appetite or loss of appetite entirely. If you experience chronic nausea, vomiting or weight loss, be sure to seek out a nutritionist to discuss options for increasing nutrient intake in a way that your body can handle and maintain. Other problematic side effects can occur in the GI tract – diarrhea, constipation and the like. Try altering the time of day when you take the medication, which may alleviate appetite or GI side effects.

Many cutaneous lymphoma patients experience extreme fatigue as a side effect of treatment. Anticipate it and pace yourself, building rest periods into your day as needed, and adjusting your work schedule wherever possible. Reorganizing your life to accommodate the changes that come from this disease and its treatments is important. It is also essential to focus on eating right, getting enough sleep and being kind to yourself rather than checking things off a regular to-do list and pleasing others. Self-care

is essential now and will affect the outcomes of your treatment and healing process.

If you experience treatment-induced depression, talk with your physician and don't hesitate to request antidepressants to help boost your mood and energy. Always maintain hydration. Dietary supplements and protein drinks can help maintain nutrient intake and prevent weight loss.

Generally, side effects may be more or less intense at times, some with cumulative side effects, and some worsening as treatments increase. Patients should understand that each specific treatment protocol leads to its own menu of side effects, so communicate with your doctor.

Skin-related issues can be addressed with soothing emollients, extra moisturization, and increasing fluid intake to keep the skin moist. Apply moisturizers immediately after bathing. Wear non-irritating clothing, and protect your skin from the sun. Watch for signs of infection and report any as they appear. Protective clothing and/or protective dressings may help if a particular area is troublesome or painful.

For excessive itching, antihistamines are available and can offer relief. Good skin care goes hand in hand with healing. Apply topical agents that your healthcare provider prescribes, avoid scratching lesions, and take recommended antihistamines.

If you experience heat or a burning sensation in the skin, there are remedies that can help. Cool soaks, moisturization, and cooling agents with menthol can be helpful. In addition, consider cold compresses or ice applications for severely affected areas.

Always check with your doctor or a pharmacist or both before using any over-the-counter products to make sure they do not contain harmful ingredients.

Chapter 11

Skin Care

3

Cutaneous lymphoma, as well as some treatments for this disease, can make skin dry, itchy, and scaly. Because cutaneous lymphoma occurs in the skin, with effects that can make the skin irritated, the skin care recommendations for patients are similar to those for patients with other chronic skin conditions such as eczema. Following you'll find tips to help with your skin care routine:

Moisturizing

Adequate moisturizing is a very important part of keeping skin healthy as it helps thicken the barrier function and keeps our skin feeling comfortable. Keeping skin moisturized and decreasing dryness can alleviate itch, too. A simple and effective way to combat dry skin is to frequently apply moisturizers or emollients.

With so many different moisturizers on the market today, it may be difficult to decide which ones to use. Here are some tips to use when comparing products:

- Ointments and creams provide the greatest moisturizing power. They are the best moisturizing products to use because they contain a high content of oil that leads to greater penetration and more staying power.
- Avoid lotions as they are made with mostly water and little oil. Avoid gels as they contain alcohol or acetone that can be drying to skin. Avoid moisturizers that contain perfume and dyes.
- Apply moisturizers frequently, at least 2 to 3 times daily, to keep skin from drying.
- You may need to try different products before finding those that work best for you.

Moisturize the skin while damp because moisturizing lotions and lubricating ointments can trap water against the skin and provide longer relief from dryness. When skin gets dry and flaky, apply a lubricating ointment with lanolin such as petroleum jelly or Aquaphor®. Patients often need to lubricate and moisturize skin many times daily.

Dryness

Dryness accompanies almost all presentations of cutaneous lymphoma. Because of this, dryness (also known as xerosis) is the most common cause of itching, which contributes to a high degree of patient discomfort.

There is, of course, wide variability as to how dryness shows up with cutaneous lymphoma. Some patients have dry patches primarily during colder months when humidity is low. Other patients experience shedding of dry flakes of skin throughout the year as their disease involves more and more of the skin's surface. In patients with extensive skin involvement, especially those with redness (also known as erythroderma), diffuse shedding of skin can occur (also known as desquamation).

This can be concerning for patients. Some feel embarrassed when skin noticeably sheds or flakes in public and at home. These feelings are understandable and completely normal. Patients can cope with these symptoms in a variety of ways including lubricating the skin with thick layers of ointment-based products such as Vaseline® or petrolatum, which can reduce shedding and scaling for at least 2-5 hours before needing to reapply.

Adding fragrance-free bath oils to bath water and soaking for 10 minutes several times a week can ease flaking and shedding for some patients. Be aware that this can cause skin to be very slippery so patients should be careful when emerging from the tub.

Over-the-counter products that contain lactic acid can help remove dry flakes from scaly skin. Most of these products contain 12% lactic acid in a fragrance-free lotion (an example is AmLactin® lotion and there are generic equivalents).

Itch

Most people with cutaneous lymphoma experience itching (also known as pruritus) and often are unsuccessful in finding relief from this chronic, aggravating symptom. Why are there no good treatments available to relieve itch? The reason is that remarkably little was known or investigated about the basic mechanisms that underlie itch until the past several years. The medical community may not have recognized the

widespread nature and importance of the problem and the fascination that comes along with understanding itch. That is changing rapidly.

Patients who experience itch will begin scratching the area that's itching, which sends a signal to the brain and back to the skin to initiate an itching frenzy. It can be helpful to apply an ice pack, bag of frozen vegetables, or crushed ice in a Ziploc® bag covered in paper towel and apply it to the itchy area for as long as 10 minutes. This will "put out the fire" so to speak. Think of itching in this disease like a wildfire – if we can eliminate the instance of itch, we can prevent it from spreading all over the skin.

For most patients with cutaneous lymphoma, itching can range from a minor irritation to a tormenting sensation that can significantly decrease a patient's quality of life. Cutaneous lymphoma-related itching is particularly troubling since it can start small and take over the body. In a study conducted by the late Dr. Marie-France Demierre of the Boston University School of Medicine, 88% of cutaneous lymphoma patients ranked itch among the top causes of distress associated with this disease.

Pruritus is a physiological condition at its root, and appropriate treatment is more likely to be prescribed if the degree of suffering is explained in detail to your physician. When meeting with your doctor, try to describe the severity of itchiness on a scale of 1 to 10, with 1 being little to no itch and 10 being unbearable and preventing smooth daily functioning.

Although a definitive cause for itch has yet to be determined, some treatments are available. A common first-line treatment is antihistamines. Some options include Allegra® and Claritin® for daytime use or Benadryl® and Atarax®, which are more commonly used at night because they have sedative properties. Some of these medications can be obtained over-the-counter while others require a prescription. These medications block redness, swelling, and itch. For most sufferers, itching becomes noticeably greater just prior to falling asleep, so sedative antihistamines can be particularly effective. There are easy home remedies to alleviate itch, too. Soak for 15 minutes in an oatmeal bath. Apply a cold compress to a particularly itchy area to calm irritation and reduce the urge to itch. Apply open-wet dressings

which are a simple, safe, and effective way to alleviate itch as well as decrease redness, burning, and weeping of skin lesions. Ask for detailed instructions about how to apply these dressings when you visit your healthcare provider.

There are other medications that help alleviate itch. Some options are:

- Gabapentin (Neurontin®) is an anticonvulsant prescribed for individuals prone to seizures, which has been effective in treating itch.
- Aprepitant (Emend®) is a prescription medication used for preventing chemotherapy-induced nausea and vomiting, which has been shown to be effective in reducing itch.
- Phototherapy is a viable treatment option for patients with mycosis fungoides, especially those suffering with itch.
- Topical steroids may be effective when used in conjunction with other treatment methods but tend to be impractical in treating severe cases due to the large surface area.
- The most effective over-the-counter lotions for less severe cases are those that contain menthol as its cooling properties can overpower the itching sensation. Be cautious of using analgesics as they have been shown to aggravate itching episodes.

In addition, some relief of itch has been reported through alternative methods such as acupuncture and biofeedback.

Fissures

A fissure is a straight or linear crack in the skin, which often extends into the second layer of skin, where it causes considerable pain and discomfort. These primarily occur on the palm side of the fingers and hands. These fissures can make it difficult to use fingers for fine motor skills like dressing, writing, cooking, or eating. Fissures can happen at any time, to anybody, particularly during winter and especially in individuals who have thick, scaly skin on their palms because of an illness like cutaneous lymphoma.

Most physicians believe this occurs in patients with scaly skin because a small crack in the skin gets infected with bacteria, particularly staph, and that causes a crack to widen and become more painful. It happens more often in winter than summer because the humid conditions of the

summer minimize fissuring by virtue of increased moisture.

Patients can take preventative measures to avoid fissures by keeping thick, scaly hands and feet moisturized frequently throughout the day with fragrance-free lotions or a thick layer of petroleum jelly products. This may include applying a thick layer at bedtime to palms and soles and sleeping with white cotton gloves or cotton socks.

Once fissures form, it's important to clean them at least twice a day with soap and water and apply an antibiotic ointment to cracks or fissures to speed healing. Patients should first try an over-the-counter product like polysporin. Most dermatologists encourage patients to avoid triple antibiotic ointment (such as Neosporin®) because the neomycin ingredient in Neosporin® can be an allergen that causes a rash. If a 1- or 2-week trial of double antibiotic ointment does not improve fissuring, patients should consult with their physician for prescription-strength topical or oral antibiotics.

Occasionally, a fissure is so deep and wide that physicians may instruct patients to use superglue to glue the fissure together. If instructed to do so, patients should clean the fissure with soap and water and dispense a tiny droplet of superglue in the fissure, pinching surrounding skin together for 60-90 seconds to help close it. It dries very quickly. However, patients need to be careful not to glue their fingers together. In addition, consider using New-Skin®, an antibiotic solution containing a light adhesive that also provides a barrier over fissures and a mixture of chemicals that creates a polymer layer which binds to the skin, keeping away dirt and germs and retaining moisture. Look for products named liquid band-aid or the like.

Infection

Skin infections are not uncommon in cutaneous lymphoma patients. Some patients with more extensive skin involvement may find that their skin is colonized with a bacteria called staphylococcus aureus. While some forms of staph bacteria exist normally on our skin, this version is the most common bacteria to infect the skin of patients with cutaneous lymphoma. When they occur, infections usually arise in skin lesions of cutaneous lymphoma. Infection is the greatest concern for cutaneous lymphoma patients because, if left untreated, its consequences can be life-threatening.

With that in mind, it's important to recognize the signs of skin infection and know when to contact your physician. Signs of skin infection may include the following:

- A red area on the skin that is painful, swollen, and may be scabbed over or weeping fluid.
- Tender redness surrounding a skin lesion.
- A skin lesion that does not itch but hurts.
- Lesions that develop a thin, yellowish crust.

While waiting to see your physician, increase the frequency of your bathing or showering from once daily to perhaps twice daily and apply double antibiotic ointment to skin lesions that have become crusted and tender.

You'll want to urgently contact your physician if any of the following occur (which could indicate the beginning of cellulitis or blood infection):

- You develop fever and chills associated with abrupt onset of fatigue and weakness.
- All of your skin lesions suddenly become tender and red, especially with streaks of redness, extending from the lesions toward your trunk (armpits or groin).

Bathing and Showering

When bathing or showering, be sure to use lukewarm water – not hot – as hot water tends to melt the natural oils from our skin that keep it hydrated and can leave our skin drier than before. Hot water also causes a surge of blood flow to the skin, which can increase itching once patients emerge from the shower or bath. Excessively hot water may temporarily relieve itch, but it is not recommended because it may aggravate skin and worsen itch long-term.

Keep baths and showers brief, no longer than 15 minutes. Also, the best time to apply emollients is after bathing, when skin is still moist. Applying moisturizer (or topical medication in an emollient) on damp skin helps seal hydration into the skin's outer layers.

Soaps

With regard to soaps, less is better. When patients feel the need

to use soap, try a moisturizing soap that contains extra oils. Avoid heavily-fragranced soaps because, when a product is infused with fragrance, it must first be dissolved in alcohol, which is drying to the skin. Fragrances can be irritating, as well, and potential allergens. Choose soaps and moisturizers that are labeled fragrance-free (Dove®, Eucerin®, Lubriderm®, Curel®, CeraVe® and Cetaphil® are some examples). Avoid antibacterial or deodorant soaps as they may be too drying.

Laundry Detergents

Laundry detergents can affect skin, too. Be sure to use a fragrance-free detergent. Also, fabric softeners often have fragrances so look for one that is fragrance-free. Fabric softener sheets added to the dryer are often the worst product for patients with sensitive skin because the fragrances directly coat clothing, which comes into direct contact with the skin and can be a constant source of irritation. Try adding vinegar (1 teaspoon per quart of water) to your laundry rinse cycle. This helps remove all the soap from your clothes, which may help lessen skin irritation.

Sun Protection

Too much sun is damaging to skin. Use sunscreen, wear a hat with a brim, and consider wearing long-sleeves and pants year-round. If you receive light therapy as part of your treatment, your healthcare provider may advise you to wear UV-blocking sunglasses. However, for some people with cutaneous lymphoma, small amounts of sunlight may actually be good for your skin. Discuss this with your healthcare team to determine which protocol is best for you.

Other Tips

You can keep your skin comfortable by also following these helpful tips:

- Wear loose-fitting, comfortable fabrics that "breathe." Cotton is best. Avoid rough, scratchy fabrics like wool. Avoid tight-fitting clothing.
- Do not scrub skin or rub harshly.
- Keep fingernails short to prevent infection and skin damage.
- Avoid getting over-heated. Sweating worsens itch.
- Find ways to manage stress as stress can trigger flare-ups in cutaneous lymphoma and increase itching.

PART 4: LIVING WITH CUTANEOUS LYMPHOMA

Chapter 12 Overview

4

You have cancer.

Those three words can unleash a riptide of emotions, from disbelief to anger to sadness to fear. All those emotions and more are normal and can be allayed by asking questions, gaining information, and talking with individuals who have either experienced the disease or understand its normal course of action.

Many patients say they experience denial when they first hear the diagnosis. “What do you mean I have cancer?” Cutaneous lymphoma does not seem like cancer, feel like it or look like cancer the way we have come to understand it. Other patients feel an intense desire to fix it – find the treatment or medication that can make it go away. The reality is that cutaneous lymphoma is a chronic disease with a high survival rate but no cure – at least not yet.

Over the course of your disease, there may be times when symptoms are present and quite intense and other times when you may experience a period of remission, sometimes many years long. At those times, patients feel that this is a disease that is entirely livable. However, during the outbreaks, it can be uncomfortable, debilitating and depressing. Be prepared for a roller coaster of emotions and physical feelings.

Also be prepared to try a variety of treatments before finding the one or combination of treatments that work for you at that point in time. Treatments may change over the course of living with cutaneous lymphoma and new options are steadily becoming available.

Make sure to work closely with your healthcare team to determine the best course of treatment. When outbreaks do occur, realize that you may find lesions or plaques or other presentations that appear in places that others can see. Patients who were formerly confident about their appearances may become self-conscious when they find skin lesions on noticeable areas like the face, neck or leg.

Any chronic disease changes your life significantly, and cutaneous lymphoma is no different. You may face physical, logistical, and emotional hurdles because of your disease. Talking with trusted friends and family, your healthcare team, and others close to you can ease the challenges and make it easier for you to ride the waves of your disease.

Physically, you may experience discomfort or pain at times – from the illness itself or from treatment methods. Here are some common physical problems patients experience:

- Severe itching – you may lose sleep because of it.
- Skin may feel hot and sore – which can be a sign of infection.
- Skin may flake or burn.
- Skin tumors may become inflamed.
- Sleeping can be difficult because of itching or discomfort.
- You may have trouble finding comfortable clothes.
- Following your normal routine may take extra time because of additional skin care steps.
- You may have trouble using your hands because of scaling and cracking.
- You may not want to work or exercise because of fatigue or the condition of your skin.

In every situation, talk with your healthcare providers about how to manage or ease symptoms. There are ways to control symptoms and side effects and treat infections. Ask your doctor about medications that can help calm these discomforts.

In addition to treating symptoms and discomfort, distract yourself with music or an energizing walk outdoors. Keep a diary to record your feelings and symptoms. Share this information with your support team. Some people find that the cancer itself does not make them sick but medications

or treatments might. Communicate this to your physician so that you can try other treatment methods to alleviate negative side effects.

Cutaneous lymphoma is a disease that can change the way you look. Dry patches, skin redness, plaques, skin ulcers, and tumors can show up anywhere on the body. Chronic itching and discomfort, plus a change in appearance, can alter how you feel about yourself. You may lose interest in socializing, which can lead to feelings of loneliness or depression. That's when it is extra important to talk with someone and share your feelings with others who've experienced what you're going through.

Some patients feel at first like they are broken individuals. Eventually, they come to accept their diagnosis and not let it define them. Attitude does affect treatment outcomes.

Ultimately, know that it's ok and normal to have fears, concerns, and feelings of frustration. You do not have to face this disease alone. Gathering supportive friends and family around, and asking others for help, are two ways to ease fears and challenges.

Consider hiring someone to take care of household or yard chores when you are not feeling up to it. And if things get increasingly difficult, your healthcare provider or insurance company can recommend skilled-care individuals to help with skin care, dressing changes, or to check on your condition.

Emotionally, you may feel a roller coaster of feelings over the course of your disease. At times you may:

- Feel fear, anger, or concern
- Not believe you have cancer
- Feel out of control and unable to care for yourself
- Feel sad, helpless, guilty, or lonely
- Wonder if you will live or die
- Become depressed

These and other feelings are normal and they are ok. Nothing is wrong with you if you experience a variety of intense emotions as you learn to live with a chronic disease.

There are many ways to help yourself, including the following:

- Learn as much as you can about your diagnosis and treatment options. Knowledge is empowering and can help you feel more in control of your situation. Ask questions!
- Find a support group. Like-minded individuals who have experienced or are experiencing the same things can be great to share feelings with, offer coping tips, and learn more about disease and treatment options. The Cutaneous Lymphoma Foundation is a great resource for finding support.
- Talk with someone one-on-one – a doctor or nurse, counselor, spiritual advisor, close friend or relative.
- Have hope. Some research suggests that hope may actually help the body fight cancer and heal. Remember: more people are surviving cancer today than in the past, and many people with cutaneous lymphoma lead active, normal lives, even during treatment.

Chapter 13

How to Tell Family and Friends

“Telling family and friends that you have cancer is worse than having cancer,” says one patient. “You see their face and know you just ruined their week. They look at you differently, and it also makes them think ‘Hey, if he got it, and he’s always been healthy and active, it could happen to me.’ It makes people consider their own mortality.”

To make matters more complicated, cutaneous lymphoma is not like other cancers. It is a chronic, live-a-long-time-with-it disease and most people understand cancer to be dire and often deadly.

Friends may look at you and say, “Wow, you look great – you must be doing fine!” When, in reality, you may feel awful. Or, it could be a good day, after a sequence of bad days. Many cutaneous lymphoma patients look fine but feel terrible. Patients can become tired of explaining again and again about their disease.

Telling family can be an even tougher task because, again, with their common knowledge of cancer, they are likely to be fearful hearing this diagnosis. Everyone responds differently and some people may become distant or go into denial. Expect to do a fair amount of educating the people around you so they can become sensitive to what you are going through. Encourage them to contact an organization like the Cutaneous Lymphoma Foundation (www.clfoundation.org) to obtain their own information or speak with someone who can help them gain an understanding of what you are going through.

After people accept the reality of your diagnosis, you may find it challenging to explain symptoms like itch. Itching can be mind-boggling and unexplainable to others, especially the chronic component of it. Many patients claim that dealing with a symptom like relentless itching can be frustrating and even a mental struggle – something that you cannot explain to others.

You may find that the people who are most supportive are not the ones you would have expected. Many patients say that those individuals who are there for them the most are acquaintances or neighbors or members of their faith community, people they would not have considered turning to, whereas some family or close friends may be surprisingly distant and unsupportive. Accept this at the beginning. People deal with serious diagnoses in a variety of ways and an inability to cope with a friend or loved one's disease is their problem, not yours.

While you are managing your disease, try to not fall into the trap of managing the emotions and reactions of those around you. When someone is not supportive, work through your disappointment and move on to those people who are supportive. Surround yourself with only those people who help you, not hinder the healing process.

Facial outbreaks can make it difficult or painful to shave, eat or even talk. Such symptoms can affect your social life. Some people prefer to remain at home during such outbreaks as people aren't always kind when they see them. For formerly social people, this can be a devastating change – to be stared at, like an oddity, and some people choose to adopt a reclusive position during outbreaks. This can be emotionally difficult for people who prefer to be very social.

It can be hard to make plans. Some patients find that, on a good day, they schedule an outing or a get-together with friends but, when the date arrives, their symptoms render them unable to fulfill the promised activity. Friends should be understanding. There will be times that you can keep plans, take vacations or otherwise make good on a scheduled outing, and there will be times when it's just not possible.

Ultimately, it is imperative to surround yourself with people who care about you and try their hardest to understand what you're going through and provide the kind of support you need. Whether it is a local community organization, family group or faith organization, find a place that provides non-judgmental support and rely on those individuals when the going gets tough. Find additional, professional support and assistance if you need to supplement the support from family and friends. A professional psychologist or other type of healthcare provider can assist in working through disturbing feelings and depression.

Chapter 14

Sexuality

Being intimate can be challenging when you have cutaneous lymphoma for the simple reason that plaques, lesions and rashes can be so uncomfortable that you don't want to be touched. Also, sometimes people with cutaneous lymphoma feel self-conscious or uninterested in being intimate because of changes to their physical appearance. Some symptoms make the skin feel so raw that a physical experience would be aggravating. From itch to burning to lathering up with ointment after a shower, the details of this disease can surely create an obstacle to intimacy.

Couples work through this. There are times when you just won't be sexual, and hopefully your partner understands this. Other times, when there aren't flare-ups, you'll likely feel as sexual as you normally would. Some younger patients even go on to have children despite their disease.

Just like you need a solid support system around you to help you weather the ups and downs of this disease, you also need a partner whose love and understanding runs deeper than the physical. Says one patient, "When you have a disease, any kind of terrible disease, you need a partner who's very, very understanding. It's frustrating, from the care side, to not know what you can do to make the person you love feel better."

Communication is key throughout the course of this disease. Letting your partner know when it's ok to touch and when it's not, explaining gently that it's not a rejection of the other person but a symptom of the condition of your skin, is important. As one patient says, "You have to tell your partner, 'I love you with all my heart, but I can't explain what I'm going through' and I'm sure the partner will understand, knowing that you love each other." Riding the roller coaster of a chronic disease can actually help you grow stronger in love.

Chapter 15

Integrative Medicine

Integrative medicine is the methodology of integrating all aspects of care – from traditional Western medicine modalities to acupuncture, homeopathy, Chinese medicine, ayurvedic, yoga and more. Complementary and alternative medicines are therapies that may assist patients in coping with cancer, treatments, and side effects. Doctors do not recommend using such therapies in place of traditional medical care. Some effective methods to combat treatment side effects and ease tension, anxiety, and other illness-induced emotions include meditation, yoga, acupuncture, exercise, nutrition, and relaxation techniques.

TAKING CARE OF THE WHOLE PERSON: BODY, MIND AND SPIRIT

Today, the definition of a cancer survivor has dramatically changed. The Institute Of Medicine defines a survivor as: Any individual from the point of their cancer diagnosis moving forward is a SURVIVOR. The goal is to help individuals not only SURVIVE with their cancer but THRIVE in the face of a life-limiting or life-threatening illness as long as possible.

Therefore, it is essential to decrease emotional stress and improve quality of life. Patients and families are often so focused on “making it” through a course of treatment that there is not much focus on other important aspects of life. However, we cannot heal the body if the mind is muddled and the spirit unfocused.

It is imperative to assess how a cancer diagnosis affects the “whole” person. What happens to a patient on every level – physical, behavioral, emotional, cognitive? Integrative medicine modalities can help achieve that ever-important balance of mind-body wellness.

In 2007, the Institute of Medicine published a report entitled *Cancer Care for the Whole Person: Addressing the Psychosocial Health Needs of Cancer Patients*. This report reveals how important it is to ensure a person’s psychosocial health, and the impact psychological well-being plays in the course of cancer. Cancer doesn’t occur just to the patient; cancer affects every member of a family.

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additional and updated information.

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The following mind-body techniques have proven helpful for patients and family members when facing a major life stress such as cancer:

Stress Management

There are many effective ways to manage stress. While one patient finds a relaxation CD soothing, another may find the sounds of breaking waves stressful. Yoga works for some people, but others are too tired so they fall asleep when the class takes them down to poses on the floor.

Keep in mind some general thoughts as you develop coping mechanisms to manage stress that can work for you. Do not allow your treatments to overtake you. Try to stay organized so you do not feel out of control. Observe and respect the natural limits of your body. If you are tired – rest!

Review your normal routine and learn what makes you tick. What stresses you out? What soothes you? Understanding yourself and having realistic expectations of your nature will guide you in determining effective coping methods. Look at your past efforts to manage stress and consider what has or has not worked. Know your strengths and exploit them. Ask for help and take suggestions; other people offer great ideas that you may not be considering. Most importantly, never let having cutaneous lymphoma become the most important thing in your life. You can have a normal life once you accept your situation.

Managing Anxiety

Anxiety can be one of the toughest emotions for patients and loved ones. Anxiety often peaks around the time of doctor visits or when new symptoms arise. This is completely normal. Sometimes anxiety fades; sometimes it does not. A recent study of anxiety found that more than one-third of patients in remission reported levels of clinical anxiety about the possibility of relapse. It's normal to be concerned about your disease.

The best way to manage anxiety is to identify when it is at its highest for you. Then, there are numerous techniques to manage it. Do not suffer alone. Seek support from a mental health professional. Talk with others who have cutaneous lymphoma or have battled it in the past and who share other characteristics with you – age, geography, family situation, etc. People with indolent (slow-growing) lymphomas learn to adapt to the cycle of starting active treatment, finishing treatment, wondering if the treatment worked, re-establishing a life routine and then wondering when disease

will return. You will discover your own unique adaptation. If you are newly-diagnosed, take solace in knowing that most people feel the shock of diagnosis. Being thrust into the world of the unknown peaks at diagnosis, which means it gets more manageable over time.

Relaxation Techniques

Herbert Benson, MD is considered the father of the relaxation response. He wrote about the importance of relaxation in his book *The Relaxation Response*. Stress comes from any outside force or event that affects our body or mind. There is good stress, which is healthy and provides a sense of fulfillment, and there is bad stress, or distress. In stressful situations, the brain jumps into the fight or flight response, preparing a person to handle dangerous situations. Adrenaline surges, increasing heart rate, blood pressure, and muscle tension.

Relaxation techniques offer strategies to help manage stressors. One technique includes basic diaphragmatic or belly breathing - breathing fully into your lungs and expanding your belly. Belly breathing essentially shuts off the fight or flight response and triggers a relaxation response. The goal is to learn to recognize stress-induced rapid breathing and instead take deep breaths to create calm.

Guided Imagery

Imagine lying on a beach under the warm sun, a cool breeze caressing your face. You are listening to the ocean lap at the shore. Imagine that you are sitting in front of a fire on a cool autumn night. The fire crackles and sparks. You stare at no particular point but rather to the flicking orange flames. The night sky is filled with sparkly stars. All is quiet.

Visualizing images like these may cause a person to feel less distressed, taking their minds away from a stressful situation. When dealing with a cancer diagnosis, our minds may race with conflicting, scary, unanswerable thoughts. At such a time, transporting the mind to specific soothing imagery allows us to retreat to a relaxing situation.

Guided imagery is integrated into cancer care in a variety of ways. Patients may develop guided imagery that includes seeing their immune system as “pac men” cruising through their body and eating up cancer cells. Or, they may see their tumors being melted like ice under a hot sun. Perhaps they choose to visualize their immune system as a surveillance system that recognizes intruders (cancer) and destroys them on impact.

For some, it's as easy as seeing a white light or healing light enter the body and heal cancer cells, leaving their bodies healthy and strong. Research shows that just imagining an event can result in the brain actually experiencing it as though the event were happening.

Medical Hypnosis

Medical hypnosis is defined as a state of focused awareness. This is simply a relaxed state where individuals “put to sleep” thoughts from their conscious mind and tap into a deeper level of consciousness to increase focus. Similar to relaxation and guided imagery, in medical hypnosis a patient hears a set of suggestions that have meaning for that individual, transporting them into a calmer state of being.

Mindfulness

Modern Western psychology has many definitions of mindfulness including “a psychological quality that involves bringing one’s complete attention to the present experience on a moment-to-moment basis.” In a fast-paced world, with scary news like a cancer diagnosis, it becomes easy to be preoccupied with what the future may hold or what the next test, scan, or treatment will reveal. Mindfulness allows us to be present and disseminate random, scary, unknowable thoughts coursing through the mind.

Tony Horton, a trainer and developer of the popular P90X exercise regimen, begins his yoga workout by saying: “Forget what happened prior to starting, let go of what you need to do after, and just allow yourself to be in the moment and be ready for a ride you won’t forget.” A core tenet of yoga practice is learning to be mindful and in the moment. Truly, the past is gone, the future has yet to exist, so all we really have is this moment. If we can embrace it, it becomes easier to set aside fears and “what ifs.”

Yoga

Yoga, an ancient tradition originating in Central Asia, is the practice of engaging mind, body, and spirit in the present and with clear focus on the worthiness of an endeavor.

Yoga has grown significantly in the West. Today, more than 15 million individuals engage in a yoga practice. Yoga is ranked as the 6th most common complementary/integrative medicine therapy in the U.S. cancer survivor population and the 3rd most common practice overall behind deep breathing and meditation.

Practicing yoga during cancer treatments can resolve insomnia, improve mood, and enhance quality of life. Additional benefits include enhanced breathing, improved appetite and bowel habits, increased sense of peace and tranquility, and fewer side effects. A recent study found that lymphoma patients who practiced yoga had improved sleep quality and decreased use of sleep medications.

Watch and Wait: Living with the Unknown

Watching and waiting can be hard; no one handles “waiting” inherently well, especially when dealing with cancer. Some people refer to this as “watch and worry.” A study of young adults with relapsed/refractory lymphoma in their twenties revealed that those with indolent disease adapt to “living in the gray” by finding a balance between knowing lymphoma will return at some point and not letting worrying about “when” affect daily life.

Some people find balance by investing wholly in personal relationships, fulfilling work, and healthy living. A reasonable first step is to acknowledge that it is scary to have an incurable cancer. From a place of acknowledging that this is not what you choose, you will identify strategies for living your life to the fullest.

Philosopher Paul Tillich suggested that anxiety of the unknown – that which can never be known - is the toughest of all. In a scenario where physicians do not have the ability to predict when, if at all, your disease may require treatment, you are left with the task of finding a way to live with the unknown.

Today there are many options for adding to your care and support system while living with cutaneous lymphoma. Check out your local gym, yoga studio or holistic health center and try a new class. See what works for you and incorporate that into your overall long-term healthy living program.

LIVING WITH CUTANEOUS LYMPHOMA: PATIENT AND CAREGIVER STORIES

“Much has changed since I learned in my late twenties what caused the red, scaly patches that had appeared on my hip, stomach and breasts for about five years. It wasn’t eczema, psoriasis or tinea, as several dermatologists assumed. It’s mycosis fungoides, a 1983 biopsy finally revealed.

That was before Google, before medical websites, before the Cutaneous Lymphoma Foundation and before I had two children. But one important thing hasn’t changed: I remain at Stage 1A of a disease that’s far less scary than it seemed 28 years ago.”

Laurel Miller Carlson
Annandale, VA
Patient of 30+ years



“As a caregiver to my 63 year-old mother, who was diagnosed in 2009 with cutaneous T-cell lymphoma (CTCL), I was informed of the Cutaneous Lymphoma Foundation during my mom’s initial oncology consultation. The Foundation’s website has been a lifeline for my family through our journey. My mom’s battle is not unlike many others fighting this disease. I remember her having these “flare ups” that included rashes, terrible itching, pain and swelling. She was biopsied, diagnosed with eczema and treated with steroids.

Being the caregiver to a loved one stricken by a rare disease is so challenging. Watching my beautiful mom suffer, feeling so helpless, so afraid of hurting her more, is devastating. I have worked hard to do everything I can do to find resources and support to ensure that her quality of life is the best it can be. One way I have done that is to make contact with the CTCL-MF Listserv, an online support group for patients and caregivers. Doing this marked a turning point in the quality of care my mother received. I contacted the listserv with

questions regarding mom’s fragile skin and how best to treat her. The responses to my questions were immediate, so helpful and overwhelming. I was not alone. There were many others willing to help, to share their lives and personal journeys with me, to share what techniques gave their loved ones relief. I gained renewed strength, energy and, most importantly, hope.”

Julie Garner
Atlanta, GA
Caregiver



LIVING WITH CUTANEOUS LYMPHOMA: PATIENT STORIES

"As a psychologist by profession and a researcher by nature, in an average day, I probably Google at least thirty topics. I didn't Google at all, though, after a biopsy suggested I had mycosis fungoides, the most common type of cutaneous T-cell lymphoma, until I was definitively diagnosed a month later. I knew that if I found something frightening, I would get lost in the "what ifs." So, to manage my fear, I asked my husband, Bob, as well as a close friend to sift information and tell me what I needed to know - especially anything reassuring.

I've drawn on my training as a psychologist to get through the diagnosis and everyday living with cutaneous lymphoma. I use relaxation and stress management techniques and focus on those things I can control, instead of allowing myself to dwell on the "what ifs." Reaching out to family and friends is incredibly helpful, as is helping others."

Geraldine Barton
Putnam County, NY
Newly-diagnosed patient



"Gathering information, evaluating facts and interpreting those facts are essential functions of my work as an attorney. But when it came to learning about my own skin rash diagnosis, I was unprepared, unnerved and very scared at first.

After a 2003 biopsy of inflamed skin samples confirmed mycosis fungoides, my wife and I naturally jumped on the Internet. Big mistake! Random searching can be the worst way to start. We found distressing pictures and alarming stories, but, initially, not reassurance about a non-fatal diagnosis that is manageable.

It was a huge relief to see more even-handed information from

respected medical websites and then the Cutaneous Lymphoma Foundation when we looked for treatment options. I live a full, active life that includes spinning and weight workouts at a gym as well as coaching my daughter's basketball team and son's baseball team.

My wife's tremendous love, support and patience have guided my personal journey with this disease. Although I am not a strongly spiritual person, I know that support and prayers from friends and family members contribute to my positive attitude. My medical outlook remains promising and my personal perspective is that "every day is the gift of a new day" - a cliché that I know is a true and guiding mantra. Though I'm just 46 and expect to be around a long while, we've expedited things we want to do as a family - such as a three-week trip through Europe."

Joseph Eischens
Kansas City, MO
Patient of 8 years



PART 5: RESEARCH

Chapter 16 Overview

5

In recent years, more attention, funding and laboratory bench time has been devoted to cutaneous lymphoma research than ever before, and early clues about its biology are being discovered.

Unfortunately, we still have only a hint as to the origins of cutaneous lymphomas. Research studies aimed at measuring accurate disease frequency (new cases per year) and prevalence (number of people affected) in diverse populations and parts of the world are important to learning more on how these diseases come about, what treatments are most effective and ultimately finding a cure.

Great advances have been made in the arena of immunobiology (fundamentals of the body's immune system) of cutaneous T-cell lymphoma (CTCL) over the last several years. However, clinical research in cutaneous lymphomas has historically been hampered by a limited enrollment of patients into clinical trials due to the relatively small population of patients, previous lack of consensus definitions of disease staging and monitoring, and insufficient collaboration between specialties and institutions. Multi-institutional and multidisciplinary coordination of clinical trial initiatives is imperative to overcome this obstacle to accelerate new drug development and testing. The **United States Cutaneous Lymphoma Consortium** (USCLC, www.usclc.org) is a newly-emerging multidisciplinary professional organization with the mission of developing a US-based research infrastructure and clinical trial network to support this need.¹

The inspirational tag line of the Cutaneous Lymphoma Foundation (CLF)'s Cutaneous Lymphoma Summit held in New York in 2009, “**community, cooperation, cure**”, brought into focus the great potential of

interdisciplinary research. Advances in communication technology have already provided a platform that has enhanced international collaborations. The cutaneous lymphoma community benefits from collaboration between all stakeholders - scientists, physicians, nurses, social workers and patients - in developing coordinated strategies to address the research agenda for cutaneous lymphoma. For an overview of the advances in cutaneous lymphomas and the cutaneous lymphoma research agenda, see the Proceedings of the CLF's Cutaneous Lymphoma Summit (www.clfoundation.org/sites/default/files/publications/CLF_Summit_Proceedings.pdf).¹

A unique aspect of the research agenda of skin-based lymphomas is that it connects the worlds of dermatology and oncology. Traditionally, cancer research is funded by the National Cancer Institute (NCI), and skin research is funded through the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS), two different branches of the National Institutes of Health (NIH). There are many unique aspects of cutaneous lymphomas that affect the skin, such as itching, protein loss, and infections due to breakdown of barrier protection, which are not found in other types of cancer. **These dermatology-related aspects of cutaneous lymphoma are important and relevant in the areas of skin and cancer research.** Because they are associated with a cancer, however, cutaneous lymphoma grant applications are typically sent to the NCI where they compete against other cancer grants for more predominant types of cancer (such as breast, colon, prostate, and lung cancer), reducing the potential of research funding. One of the advocacy priorities of the Cutaneous Lymphoma Foundation is to bring awareness of this issue to these organizations and advocate a broader view regarding the eligibility of cutaneous lymphoma grant applications within and between the NCI and NIAMS. This would potentially increase the funding opportunities for cutaneous lymphoma investigators.¹

Recruitment of the best and brightest into the cutaneous lymphoma research arena ensures progress and advancement in learning more about the disease and finding new treatments. The mentoring from established investigators of individuals early in their career development is an essential element of recruiting and retaining these young researchers in the field of cutaneous lymphoma. The Cutaneous Lymphoma Foundation's **Young Investigator Award** program supports these young investigators in their pursuit of careers in cutaneous lymphoma.

The Cutaneous Lymphoma Foundation is also committed to funding promising research that can lead to improved therapies and, one day, a cure for cutaneous lymphoma. To that end, the Foundation established a new **CLF Research Awards Program** in early 2012, the first dedicated exclusively to funding cutaneous lymphoma research.

¹Source: *Proceedings from the Cutaneous Lymphoma Summit, 2009; "The State of Cutaneous Lymphomas: A Call to Action"; Stuart R. Lessin, MD, Pierluigi Porcu, MD*

RESEARCH AWARDS PROGRAM

In 2012, the Cutaneous Lymphoma Foundation established a new Research Awards Program, the first research program dedicated exclusively to funding cutaneous lymphoma research. This program will support investigators interested in conducting innovative cutaneous lymphoma research designed to investigate the causes and improve treatments, clinical care and quality of life for patients. Discovering new avenues for better therapies and, one day, a cure for cutaneous lymphoma are key aims of this program.

With ongoing support of donors, the sustainability of this program will leverage federal and industry resources and grow the cutaneous lymphoma research agenda.

We'll be sharing more about our exciting new Research Awards Program on our website at www.clfoundation.org so visit often for updates.

Chapter 17

Clinical Trials

A clinical trial is a research study designed to answer basic and clinically relevant questions about a new treatment or a new way of using an old treatment. A clinical trial provides information or data by which treatments can be measured – how effective they are (efficacy) and how safe they are (side effects).

Clinical trials are incredibly important for determining new and more effective treatments. They require voluntary participation and that each participant is fully informed about the details of the clinical trial before enrollment. Safeguards are required to ensure that each clinical trial is scientifically valid, has fair subject selection, a favorable risk-benefit ratio and ensures the respect and safety of all those enrolled.

While participating in a clinical trial can be time-consuming, the results can be potentially groundbreaking. Many of the cancer treatments we take for granted today were, at some point, studied in a clinical trial. Patients and physicians must discuss and evaluate all associated factors before deciding a course of action as there are always risks associated with any form of treatment. Patients typically choose to participate in clinical trials because they are looking for availability and access to new treatments that may be effective for them when other treatment methods have proved unsuccessful or limiting.

The medications used to treat cutaneous lymphoma are evaluated in three ways: formal clinical trials, years of post-marketing experience and case studies. In the medical literature, over the last decade, evidence-based criteria have been used for evaluating the quality and impact of published data that demonstrates a particular treatment's effectiveness. This information is published and made available for use by doctors, researchers and patients.

The best evidence for evaluating whether a treatment is effective for cutaneous lymphoma is a controlled clinical trial in which a new drug is directly compared to another, usually older, drug (the control). The best

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situation is when it is a double-blind trial, where the patient as well as the physician does not know what drug is being administered, and, at the end of the trial, data is evaluated to determine each drug's effectiveness. More common in cancer medicine are so-called open-label trials, where everyone is aware of which medication is being administered.

In addition to clinical trials, there are case studies. A case study is a publication where doctors review their records retrospectively over a course of many years to determine the numbers of patients with a certain disease and evaluate what treatments have been effective. The results are published with a general estimate of the treatment's success rate and safety. The problem with retrospective case studies is that, since the information was not collected in real time going forward, data may be missing or be inaccurate. Therefore, the quality of the evidence from case studies is much inferior to that obtained in prospective clinical trials and conclusions about treatment efficacy and safety should always be confirmed prospectively.

Scientific advances and education are important cornerstones to continuing the progress in finding effective new treatments for cutaneous lymphoma as well as for continuing to monitor existing therapies or new combinations of therapies that can move us closer to finding a cure. Patients can contribute to these efforts by being open to exploring participation in a clinical trial with their physicians. By taking an active role and being a voice in support of continued governmental or private funding for new treatments and research for cutaneous lymphoma, patients can have a big impact on the future of funding new developments leading to a cure one day.

What Exactly is a Clinical Trial?

A cancer clinical trial is a carefully controlled research study conducted by doctors to improve the care and treatment of people who have cancer. A treatment that is proven safe and effective in a cancer clinical trial is often approved by the U.S. Food and Drug Administration (FDA) for use as a standard treatment if it meets one or both of the following criteria:

- It's more effective than the current standard treatment.
- It has fewer side effects than the current standard treatment.

The purpose of cancer clinical trials is to:

- Improve treatment options

- Increase survival
- Improve quality of life

Advances in the treatment for cutaneous lymphoma depend on clinical trials of new therapies or new therapy combinations. Different types of cancer clinical trials are designed to develop and test new and better ways to:

- Diagnose and treat cancer in people
- Prevent or relieve treatment side effects
- Help prevent a return of cancer
- Improve comfort and quality of life for people with cancer

Clinical trials are expensive. Organizations such as the National Cancer Institute and pharmaceutical companies usually fund cancer clinical trials.

Phases of a Clinical Trial

Phase I: Phase I studies are designed to assess the best dose, route of administration, frequency of treatment and overall safety of the drug in a small number of patients.

Phase II: Once the therapy dose is determined and shown to be safe in a phase I trial, it is then ready to be tested in a phase II study. Phase II studies aim to better define the effectiveness of the drug in a larger group of patients. These studies might be used to generate preliminary data on a drug or to confirm data to obtain FDA approval. Phase II studies also investigate whether a therapy approved for one type of disease is an effective treatment for another.

Phase III: Phase III trials are performed to determine whether the treatments developed in phase I and II studies are better than what is currently considered the "standard of care" for a specific disease. Phase III studies often require a large number of patients. Once a patient elects to enroll in a phase III study, he or she is assigned to one of two groups in a process called "randomization." In randomization, a computer assigns the treatment the patient is to receive. One group receives the current standard therapy and the other group receives the treatment that is being proposed as a replacement. It is important to remember that this randomization process is done so that each treatment arm will have

patients with similar characteristics and be free of bias. Both treatments are expected to be active. The randomization in phase III trials allows researchers to determine whether or not the new treatment is any more effective or less toxic than the standard of care.

Source: Understanding Non-Hodgkin Lymphoma – A Guide for Patients, Survivors and Loved Ones, Third Edition; Lymphoma Research Foundation

Who's on the Clinical Trial Team?

A clinical trial team is made up of doctors, nurses, social workers and other healthcare professionals. The team members:

- Check each participant's health at the beginning of the trial
- Give specific instructions for taking part in the trial
- Monitor each participant's health throughout the trial
- In some cases, follow up with patients after the trial is over

Your regular doctor or healthcare provider coordinates with the research team to ensure that other ongoing drugs or treatments you're receiving won't interfere with the study treatment.

Source: The Leukemia & Lymphoma Society; www.lls.org

Questions To Ask Your Healthcare Provider

- Is a clinical trial right for me? What are my options?
- Where does the clinical trial "fit" into the standard skin-directed and systemic therapies?
- Will my healthcare provider team be directly involved in the care during the clinical trial period?
- Will there be an opportunity to continue clinical trial agents after the study ends?
- What if I need to withdraw from the clinical trial?
- What are the requirements related to logistics, location and the visits I will need to make?
- What are the risks and benefits of this trial?
- Are there any anticipated side effects?
- What are the costs associated with the clinical trial?
- How do I make sure my insurance covers these costs?
- Will there be any anticipated costs that my insurance will not cover?
- What kind of caregiver support will be required?

Glossary Of Medical Terms

Aggressive lymphomas: Lymphomas that are fast-growing and generally need to be treated immediately; typically considered intermediate-grade or high-grade lymphomas.

Allogeneic transplant: A procedure in which a patient receives bone marrow or stem cells donated by another person.

Alopecia: Hair loss. Alopecia from systemic chemotherapy is almost always temporary; hair grows back when therapy is finished.

Anemia: A shortage of red blood cells, causing weakness and fatigue.

Angiogenesis: The process of developing new blood vessels.

Antiangiogenesis therapies: Drugs that prevent tumors from developing new blood vessels, thereby stopping or limiting tumor growth.

Antibody: A complex protein made by B-lymphocytes that reacts with antigens on toxins, bacteria and some cancer cells and either kills or marks them for removal.

Antiemetic: A drug that reduces or prevents nausea and vomiting.

Antigen: Identifying proteins located on the surface of all cells. The immune system uses antigens to determine whether cells are a necessary part of the body or need to be destroyed.

Apheresis: Process of separation of components of whole blood (white blood cells, red blood cells, platelets, stem cells, plasma) performed in a specialized apparatus.

Autologous transplant: A type of bone marrow or stem cell transplantation in which a patient receives his or her own cells (not the type of transplant recommended for cutaneous lymphoma patients).

Biologic therapy: Treatment that uses or stimulates the immune system in directing a response against an infection or disease.

Biomarker: A compound (usually a protein) used to measure the presence of a disease.

Biopsy: Removal of tissue for evaluation under a microscope for diagnostic purposes.

Bone marrow: Spongy material found inside the bones containing stem cells that develop into three types of cells: red blood cells that deliver oxygen to the body and take away carbon dioxide; white blood cells that protect the body from infection; and platelets that help the blood to clot.

Cancer: Abnormal cell growth that cannot be controlled by the body's natural defenses. Cancerous cells can grow and eventually form tumors.

Catheter (intravenous access): A device that is temporarily or permanently placed into a vein that makes it easier to give medications.

Chemotherapy: Treatment with drugs to stop the growth of rapidly dividing cancer cells, including lymphoma cells.

Chemotherapy cycle: Term used to describe the process in which chemotherapy is given, followed by a period of rest in which the body is allowed to recover.

Chemotherapy regimen: Combinations of anticancer drugs given at a certain dose in a specific sequence according to a strict schedule.

Clinical trial: A research study in which a new treatment is given to patients to determine whether it is safe, more effective or less toxic than current therapies. Clinical trials are an important part of the process of understanding diseases and have been instrumental in providing information to the Food and Drug Administration for approval of new therapies.

Combination chemotherapy: Several drugs given together to increase response rate of certain tumors.

Complete remission (CR): Term used when all signs of disease have disappeared after treatment.

CT or CAT (computerized axial tomography) scan: This imaging test provides a series of detailed pictures of the inside of the body using an X-ray machine linked to a computer.

Cure: A complete remission that lasts as long as the patient's life.

Cutaneous: Anything that is related to, or has to do with, the skin.

Cutaneous T-cell lymphoma (CTCL): 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, lymphomatoid granulomatosis, granulomatous slack skin disease, and pagetoid reticulosis, to name a few. All cases of mycosis fungoides are cutaneous T-cell lymphoma, but not all cutaneous T-cell lymphomas are mycosis fungoides.

Dermatologist: Physician who specializes in the diagnosis and treatment of skin diseases

Disease progression: The term used if the disease worsens despite treatment (also called treatment failure).

DNA: Abbreviation for deoxyribonucleic acid, an essential component of genes.

Dose intensity: A term used to describe how much chemotherapy or radiation is given over a defined period of time.

Durable remission: A remission that lasts more than a few months.

Electron beam therapy: A form of radiation therapy that only treats the superficial portions of the skin. It is highly effective in clearing all forms of lesions of cutaneous T-cell lymphoma from the skin. It can be used to treat portions of the skin or the entire skin surface. When used to treat all of the skin it is referred to as total skin electron beam (TSEB) therapy.

Etiology: The cause or origin of a disease.

Extranodal disease: A lymphoma that originates or spreads outside of the lymphatic system.

Fatigue: A decreased capacity for activity that is often accompanied by feelings of weariness, sleepiness or irritability.

Generalized disease: A cancer that has spread throughout the body.

Genes: The basic building blocks of heredity that are present in all cells. Genes are comprised of DNA and other materials.

Grade: A method of classifying a cancer on the basis of how aggressive it looks under the microscope.

Graft versus host disease (GVHD): Occurs when a donor's bone marrow (graft) recognizes the recipient of the marrow (host) as foreign. In response, the immune cells in the donor marrow attack the cells in the host. This can be a side effect of bone marrow transplantation.

Graft versus lymphoma reaction: Occurs when a donor's allogeneic bone marrow generates cells that recognize the recipient's lymphoma cells as foreign and produces an anti-lymphoma response.

Harvesting: A procedure in which stem cells are obtained from the blood or bone marrow for use in repopulating the body's cells after high-dose chemotherapy.

Hematologist: A physician who specializes in treating diseases of the blood and blood-forming tissues, including cancer. Often, but not always, hematologists are also specialized in medical oncology.

Histology: The study of tissue characteristics that may lead to identifying a specific type of tumor.

Idiotype: A unique "fingerprint" portion of an antibody present on the surface of B-cells.

Idiotype vaccine: A lymphoma vaccine that is custom-made to attack an individual patient's lymphoma and contains idiotype (unique) tumor materials and an immune stimulant.

Immune system: One of the body's defense mechanisms involved in fighting infections and recognizing foreign tissues. All cutaneous T-cell lymphomas and lymphomas are diseases of the immune system.

Immunological tests: Blood tests that detect the presence of diagnostic proteins or antigens on a tumor.

Immunotherapy: See biologic therapy.

Indolent lymphoma: Lymphoma that is slow-growing and has few symptoms. Also called low-grade lymphoma.

Interferons: Naturally occurring compounds that stimulate the immune system in infections and inflammation. Synthetic forms are used to treat viral infections, autoimmune diseases and cancers.

Lactate dehydrogenase (LDH): An enzyme measured in the blood and used as a biomarker to measure the extent or spread of cancers.

Leukopenia: An abnormally low level of circulating white blood cells resulting in the inability to fight infections.

Local therapy: A therapy that is directed to specific and limited areas.

Localized disease: A cancer that is only present in a limited part of the body – for example, the neck or armpits.

Low-grade lymphoma: Lymphoma that grows slowly and has few symptoms. Also called indolent lymphoma.

Lymph: The watery fluid in the lymph system that contains white blood cells (lymphocytes).

Lymph nodes: Small bean-shaped glands located in the small vessels of the lymphatic system. Thousands are located throughout the body with clusters of them in the neck, under the arms, the chest, abdomen and groin. Lymph nodes filter lymph fluid, trapping and destroying potentially harmful bacteria and viruses.

Lymphatic system: The channels, tissues and organs that store and carry lymphocytes that fight infection and other diseases.

Lymphocyte: A type of white blood cell. Lymphocytes, carried along by the lymph fluid, are part of the immune system and fight infection.

Lymphoma: A cancer of lymphocytes involving lymph nodes, organs and tissues of the lymphatic system (immune system). Hodgkin's lymphoma is one type of lymphoma; the other major type is non-Hodgkin's lymphoma. Cutaneous T-cell lymphoma is a non-Hodgkin's lymphoma that starts in the skin. There are approximately 61 types of non-Hodgkin's lymphoma.

Lymphomatoid papulosis (LyP): A lymphatic system disorder that manifests itself in self-healing nodules and papules ("bumps" and "spots") that come and go spontaneously. It looks like cancer under the microscope, but, frequently and for no reason, it suddenly disappears of its own accord for weeks or months at a time before reactivating.

Malignant: Cancerous – a malignant tumor is a cancerous tumor.

Medical oncologist: A physician who specializes in the use of chemotherapy, hormone therapy, and many other types of biologic therapies to treat cancer. Often, but not always, medical oncologists are specialized in hematology.

Memory cells: Types of B-lymphocytes and T-lymphocytes. After a foreign invader or unwanted cell has been destroyed, surviving B- and T-lymphocytes develop into specialized memory cells that remain on watch and can provide protection if the invader is encountered in the future.

Metastasize: To spread to other organs of the body. Cancer may spread from its primary site of origin to other sites or organs.

Modality: A fundamental type of cancer therapy, such as radiation, surgery, chemotherapy, or light therapy.

Monoclonal antibodies: Antibodies that act specifically against a particular antigen. Scientists can produce large amounts of an antibody that can be directed to a single target (or antigen) on the cell's surface. Monoclonal antibodies are used to classify lymphomas by identifying surface proteins on lymphocytes. Monoclonal antibodies are also used as therapeutic agents and have been developed to combat specific cancers including cutaneous T-cell lymphomas.

MRI (magnetic resonance imaging): MRI uses magnets and radio frequency waves to produce images of inside the body. MRIs can provide information about tissues and organs that is not available from other imaging techniques.

Mucositis: Inflammation of the lining of the tissues and organs. In the mouth, it is characterized by sores or inflammation.

Mycosis fungoides (MF): Term for the most common type of cutaneous T-cell lymphoma. It is typically a low-grade lymphoma which 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.

Myelosuppression: A reduction in the bone marrow's ability to make red blood cells, white blood cells and platelets.

Neutropenia: An abnormally low level of neutrophils (the white blood cells responsible for fighting bacterial infections).

Neutrophils: The primary type of white blood cells found in the blood that fight bacteria.

Non-Hodgkin's lymphoma (NHL): A group of several closely-related cancers that arise from the lymphatic system. Although the different types of NHL have some things in common, they differ in what the cancer cell looks like under a microscope, how the cells grow and how the tumor affects the body. Cutaneous T-cell lymphomas are a type of NHL.

Oncologist: A physician who specializes in treating cancer. Some specialize in chemotherapy (medical oncologist), radiotherapy (radiation oncologist) or surgery (surgical oncologist).

Palliation: Treatment that is given to remove or relieve symptoms.

Partial remission (PR): The term used when a cancer has shrunk in size by at least half but has not totally disappeared. The cancer can still be detected and other treatments may be recommended.

Pathologist: A physician who specializes in studying disease through microscopic evaluation of body tissues and organs (biopsy). Any tissue suspected of being cancerous must first be examined by a pathologist to confirm the diagnosis.

PCR (polymerase chain reaction): A molecular test that can identify small amounts of genetic material.

Performance status: A term used to describe a person's ability to perform their activities of daily living.

Peripheral neuropathy: Damage to the nerves. This condition can be caused by some drugs and is usually characterized by tingling and weakness or numbness in the extremities.

Peripheral T-cell lymphoma (PTCL): PTCL is a group of lymphomas defined by the types of mature-stage white blood cells (T-cells or natural killer (NK) cells) within the lymphatic system from which they arise. The term "peripheral" refers to the fact that PTCL arises in the lymphoid tissues outside of the bone marrow such as lymph nodes, spleen, gastrointestinal tract and skin. When skin is involved, PTCL can share many features of cutaneous T-cell lymphoma (CTCL).

PET (positron emission tomography) scan: A type of test that may be used instead of gallium scans to identify areas in the body that are affected by lymphoma. This test evaluates metabolic activity in different parts of the body using a radioisotope.

Photopheresis: An immunotherapy. It is a three to five hour procedure in which a portion of a patient's blood is taken out through the vein and the white blood cells are treated with PUVA (psoralen medication + UVA light) phototherapy, after which they are then re-infused into the vein.

Phototherapy: A form of skin-directed therapy that uses various forms of ultraviolet light and is often effective in clearing cutaneous T-cell lymphoma in its earliest stages, when the disease is confined to the skin (Stage I-A, I-B, II-A, II-B). Forms of phototherapy include PUVA (psoralen medication + UVA light), broadband UVB, and narrowband UVB.

Plasma cell: A mature B-cell that makes antibodies – these antibodies help the body destroy or remove toxins, bacteria and some cancer cells.

Primary cutaneous B-Cell lymphoma: Lymphomas that grow outside the nodal system, also called extranodal lymphomas, which are tumors that occur in organs or tissues outside the lymphatic system. When extranodal lymphomas originate in the skin and there is no evidence of systemic or extracutaneous disease, they are called primary cutaneous lymphomas and primary cutaneous B-cell lymphomas (CBCLs) when B-cells are involved.

Primary therapy: The first therapy given after a diagnosis of cancer.

Prognosis: The likely outcome of a disease, including the chance of recovery and survival.

PUVA: A phototherapy treatment that uses psoralens (P) in combination with ultraviolet light (UVA). Psoralens make the skin sensitive to the UVA. It is used to treat various skin disorders.

Radiation field: The part of the body that receives radiation therapy.

Radiation oncologist: A physician who specializes in treating cancer with radiation.

Radiation therapy: The use of radiation beams (X-rays) to treat a cancer. High doses of high-energy radiation beams carefully focused on a tumor will kill cancer cells. Radiation therapy (with or without chemotherapy) is sometimes used to treat cutaneous T-cell lymphomas.

Radioimmunotherapy: A therapy that is prepared by attaching a radioactive tag to a monoclonal antibody. Currently in use for B-cell lymphoma, but not T-cell lymphoma.

Refractory disease: A cancer that is resistant to treatment.

Regimen: A specific combination of drugs (chemotherapy), their doses and their schedules of administration. A regimen may also include radiotherapy.

Relapse: The return of cancer after treatment. Lymphoma may recur in the area where it first started or it may relapse in another area of the skin.

Remission: The absence of disease. A patient is considered in remission when their lymphoma has been treated and tumors have diminished by at least 50% (partial) or have totally disappeared (complete).

Risk factors: Factors that may increase the chance that a person will develop a certain kind of disease.

Sézary syndrome (SS): A leukemic type of cutaneous T-cell lymphoma. Patients usually present with SS, but rarely patients with early-stage mycosis fungoides 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.

Stable disease: The disease does not get better or worse following therapy.

Stage: The extent of cancer in the body including whether the disease has spread from the original site to other body parts.

Standard therapy: The most widely used primary therapy.

Stem cell therapy: A therapy used in experimental stages in the treatment of cutaneous T-cell lymphoma.

Synergism: The term used when two or more drugs given together provide a better anti-cancer effect than expected from the additive effects of each individual medication.

Systemic chemotherapy: A chemotherapy regime that can be a single agent drug or a combination chemotherapy. This type of therapy is usually reserved for advanced stages (Stage III and IV) that are resistant to other forms of therapy and administered orally or intravenously.

Targeted therapy: A treatment that is directed to specific genes or proteins (targets) unique or abnormally expressed in a cancer cell.

Thrombocytopenia: A shortage of platelets in the blood, which reduces the ability of the blood to clot.

Thymus gland: A gland located behind the sternum (breastbone) that enhances the reproduction and development of lymphocytes. T-lymphocytes are processed in the thymus.

Toxicities: The unwanted side effects of cancer therapies, such as a decrease in blood cells, nausea and vomiting, and hair loss.

TSEB (total skin electron beam): A form of radiation therapy that only treats the superficial portions of the skin. It is highly effective in clearing all forms of lesions of cutaneous T-cell lymphoma from the skin. Also known as electron beam therapy.

Tumor: The word tumor has more than one meaning. A tumor can be a mass or swelling of abnormal tissue, anywhere in the body. Not all tumors are malignant; some of them are benign (a good example of benign tumors are uterine “fibroids”). In cutaneous lymphoma, a tumor is also one of the three main types of skin lesions seen in mycosis fungoides (patches, plaques, and tumors).

UVB, broadband: A form of phototherapy that uses ultraviolet light involving the entire range of UVB wavelengths.

UVB, narrowband: A form of phototherapy that concentrates ultraviolet output in a narrow range of UVB wavelengths. It can be an effective treatment for patch-stage cutaneous T-cell lymphoma as well as other skin diseases.

Vaccine: A substance or group of substances meant to stimulate the immune system to respond. A vaccine can help the body recognize and destroy cancer cells. Lymphoma vaccines often combine cancer antigens with a substance to stimulate the patient’s own natural defenses to fight the disease. These vaccines are custom-made for each patient using a sample of tumor obtained from the patient’s lymph nodes.

X-ray: Radiation that is used in low doses to provide images of the inside of the body and in high doses to treat cancer.

About the Cutaneous Lymphoma Foundation

The Cutaneous Lymphoma Foundation is an independent, nonprofit patient advocacy organization dedicated to supporting every person with cutaneous lymphoma by promoting awareness and education, advancing patient care, and facilitating research. **We exist to make sure that each person with cutaneous lymphoma gets the best care possible.**

The Cutaneous Lymphoma Foundation is the only organization worldwide providing comprehensive programs and services for patients, caregivers, medical professionals and others affected by cutaneous lymphoma.

History

The Cutaneous Lymphoma Foundation was founded in 1998 by three visionary leaders: Judy Jones, Dr. Stuart Lessin, and Judith Shea. Each played a vital role in establishing and building the organization.

When Judy Jones was diagnosed with cutaneous T-cell lymphoma (CTCL) in 1990, she was frustrated by the lack of information available and wondered how other people were coping with a disease about which they knew nothing. In 1996, she created and went online with the CTCL-MF Listserv, an online support group, which grew fast as the Internet burgeoned and people became computer-savvy.

Meanwhile, Judith Shea’s husband, Lee Allen Cohen, was diagnosed with Sézary syndrome in 1994 and passed away in 1996. Frustrated by the lack of information and support during her husband’s illness, Judith created the Lee Allen Cohen Fund in his memory. Her goal was to find a way to use this legacy to provide support to others with CTCL diseases.

Mr. Cohen’s physician was Dr. Stuart Lessin, a dermatologist treating CTCL patients in Philadelphia. Judith met with him several times to discuss ways to reach her goal. After receiving information about the CTCL-MF Listserv from one of his patients, Dr. Lessin called Judy Jones and suggested that she consider starting a foundation. Remembering

Judith Shea's goals, he connected the two "Judys." Together they decided to use the Lee Allen Cohen Fund to launch the Foundation in 1998.

PROGRAMS AND SERVICES

The Cutaneous Lymphoma Foundation offers comprehensive programs and services that provide relevant, timely information and resources that deliver life-changing, positive outcomes for patients, caregivers, loved ones, medical professionals and others affected by cutaneous lymphoma. These programs include:

Patient Educational Forums

These day-long events held throughout the year in the United States and Canada provide exceptional opportunities for people with cutaneous lymphoma to receive accurate information about the disease, treatment options, access to experts in the field, and connect with other people who share similar experiences.

Website

Our website at www.clfoundation.org is one of the most important resources we offer. At anytime, comprehensive information can be found on our website about the many types of cutaneous lymphoma, treatment options, treatment centers and specialists, the programs and services we provide, research and advocacy efforts, ways to become involved in the Foundation's work, and much more.

Library of Printed/Electronic Education Materials

In addition to this guide, we offer a variety of printed and electronic education materials including fact sheets, downloadable archived teleconferences, newsletters and more. You can download or order these materials online at www.clfoundation.org or by contacting us at info@clfoundation.org or 248.644.9014.

Physician and Treatment Center Referral Network

Finding the best possible treatment and care is vital for every cutaneous lymphoma patient. Our website at www.clfoundation.org lists top cutaneous lymphoma treatment centers and specialists.

Personal Assistance via Phone and Email

Personal assistance is available at the Foundation via phone or email. If you are not able to get your questions answered via our website or this guide, or

if you just want to talk with someone about anything related to your unique experiences and how you are affected by cutaneous lymphoma, please contact us via phone at 248.644.9014, ext. 3, or via email at info@clfoundation.org.

Research Funding

In recent years, more attention, funding and science has been devoted to cutaneous lymphoma research than ever before. The Foundation has been a strong partner to researchers who are a driving force behind this change, and we are working to increase the number of dollars, scientists and research projects devoted to cutaneous lymphoma. The Foundation has funded important epidemiology and quality of life studies, and it provides funding to early investigators through its ongoing Young Investigator Awards.

Importantly, the Foundation has established a Research Awards Program, which is the first research program dedicated exclusively to cutaneous lymphoma. This program provides funding to investigators interested in conducting innovative cutaneous lymphoma research designed to investigate the causes and to improve treatments, clinical care and quality of life for patients.

Advocacy

At the Cutaneous Lymphoma Foundation, we advocate on behalf of people affected by cutaneous lymphomas to affect positive change on many issues that are important to a patient's quality of life. These issues include increasing funding of cutaneous lymphoma research, ensuring access to treatments and high-quality medical care, fighting drug shortages, and much more.

For more information about the Cutaneous Lymphoma Foundation and all of its programs and services, visit www.clfoundation.org.

Resources For Patients, Caregivers And Loved Ones

Receiving a diagnosis of cutaneous lymphoma can be frightening and challenging. Whether you or someone you love is newly-diagnosed or a long-term survivor, understanding more about the latest medical information and accessing support services can help.

In this section you'll find a variety of organizations that you can contact to obtain more information, resources and support to help you along your journey.

Cutaneous Lymphoma Foundation

The Cutaneous Lymphoma Foundation is an independent, nonprofit patient advocacy organization dedicated to supporting every person with cutaneous lymphoma by promoting awareness and education, advancing patient care, and facilitating research. We exist to make sure that each person with cutaneous lymphoma gets the best care possible. The Cutaneous Lymphoma Foundation is the only organization worldwide providing comprehensive programs and services for patients, caregivers, medical professionals and others affected by cutaneous lymphoma. Programs include our website at www.clfoundation.org, Patient Educational Forums, printed/electronic educational resources and newsletters, physician and treatment center referral network, personal assistance via phone/email, research, advocacy and more. For more information, visit www.clfoundation.org, email info@clfoundation.org or call 248.644.9014.

EMOTIONAL SUPPORT

CUTANEOUS LYMPHOMA-SPECIFIC EMOTIONAL SUPPORT

CTCL-MF Listserv

The CTCL-MF Listserv is an online support group hosted by the Association of Cancer Online Resources (ACOR) for patients, caregivers, family and friends to discuss clinical and non-clinical issues about cutaneous lymphoma. People on the Listserv share information on patient experiences, psychosocial issues, treatment practices, new research and clinical trials. You can join the Listserv by visiting the Cutaneous Lymphoma Foundation's website at www.clfoundation.org/OnlineSupport

Please refer to our website for additional and updated information.

www.clfoundation.org

Cutaneous Lymphoma Foundation

Support is an important part of overall health and wellness in addition to treatment of cutaneous lymphoma. The Foundation provides one-on-one telephone support to anyone living with cutaneous lymphoma or a loved one supporting a patient. In addition, in-person support groups are offered as part of the Foundation's Patient Educational Forums held in various cities across the country. Contact us at 248.644.9014, ext. 3 or info@clfoundation.org for personal assistance anytime.

GENERAL EMOTIONAL SUPPORT

CancerCare

CancerCare is a national nonprofit organization that provides free, professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance. CancerCare has a variety of programs in place to assist those in need. For more information, visit www.cancercare.org or contact 800.813.HOPE (4673).

Cancer Hope Network

Cancer Hope Network is a nonprofit organization that provides confidential one-on-one support to cancer patients and their families. They provide that support by matching cancer patients and/or family members with trained volunteers who have themselves undergone and recovered from a similar cancer experience. For more information, call 800.552.4366 or visit www.cancerhopenetwork.org.

Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. The CSC is an international nonprofit dedicated to providing support, education and hope to people affected by cancer. Likely the largest employer of psychosocial oncology mental health professionals in the United States, CSC offers a menu of personalized services and education for all people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone. For more information, visit www.cancersupportcommunity.org or contact 888-793-9355.

Cancer Survivors Network

The American Cancer Society created the Cancer Survivors Network, an online community of cancer survivors, families and friends. The mission of the program is to provide a "private, secure way to find and communicate with others who share your interests and experiences" and ultimately for participants to share their experiences, strengths and hopes. For more information, visit www.acscsn.org.

Chemo Angels

Chemo Angels is a volunteer organization dedicated to supporting people undergoing IV chemotherapy treatment for cancer. In addition to providing information and cancer-related resources, the organization matches patients who are going through the difficult time of chemotherapy with "Angels." Many of the Chemo Angels volunteers are cancer survivors themselves or people whose lives have been affected by cancer in some way. The function of these Angels is to bring a bit of cheer and encouragement through gestures such as notes, cards and small gifts. For more information, visit www.chemoangels.net.

Imerman Angels

Imerman Angels connects a person fighting cancer today (cancer fighter) with someone who has beaten the same type of cancer (cancer survivor). In addition, Imerman Angels also connects caregivers. A caregiver is a friend or family member who is supporting a cancer fighter. Like fighters and survivors, they may wish to be paired up with another caregiver who relates to and understands their situation. For more information, call 877.274.5529 or visit www.imermanangels.org.

FAMILY AND CAREGIVERS SUPPORT

Caregiver Action Network

The Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge. For more information, call 202-772-5050 or visit caregiveraction.org.

Family Caregiver Alliance

The Family Caregiver Alliance (FCA) is the first community-based nonprofit organization started in the United States to address the needs of families and friends providing long-term care at home. Long-recognized as a pioneer in health services, FCA now offers programs at national, state and local levels to support and sustain caregivers. For more information, visit www.caregiver.org or call 800.445.8106.

Kids Konnected

Kids Konnected was developed on the premise that when a parent gets cancer, the entire family is affected and the needs of the children must be addressed. Kids Konnected offers support, understanding, community, comfort and a safe haven while a child goes through a parent's cancer journey. For more information, visit www.kidskonnected.org or call 800.899.2866.

Straight Talk To Kids

Straight Talk To Kids (STTK) is an online resource developed by the Social Work Department of the NYU Hospitals Center. STTK was designed to assist parents, caregivers or other adult family members in talking to children when a parent or a significant family member is diagnosed with cancer or a serious illness. For more information, visit <http://cancer.med.nyu.edu/patients/patient-care/supportive-services/straight-talk-kids>.

Well Spouse Association

The Well Spouse Association, a nonprofit membership organization, advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. The organization offers peer to peer support and educates health care professionals and the general public about the special challenges and unique issues "well" spouses face every day. For more information, visit www.wellspouse.org or call 800.838.0879.

Young Cancer Spouses

The mission of Young Cancer Spouses is to bring together young spouses of adults with cancer to share information, support, and experiences. For more information, visit www.youngcancerspouses.org.

FINANCIAL SUPPORT

CancerCare

CancerCare is a national nonprofit organization that provides free, professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance. CancerCare has a variety of programs in place to assist those in need. For more information, visit www.cancercare.org or contact 800.813.HOPE (4673).

Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. In a recent study conducted by the CSC, a majority (72.8%) of patients surveyed experienced some degree of emotional distress from managing cancer care costs. To help meet the needs of the growing population of people impacted by the financial burden of cancer care, the CSC recently released the third edition of its highly acclaimed *Frankly Speaking About Cancer: Coping with the Cost of Care* book. Visit www.cancersupportcommunity.org or contact 888.793.9355 to learn more and download the book.

The Leukemia & Lymphoma Society

Dealing with cancer is hard enough without having to worry about its financial burdens. The Leukemia & Lymphoma Society Co-Pay Assistance Program helps you pay your insurance premiums and meet co-pay obligations. They also help you find additional sources of help. For more information, visit www.lls.org or contact 800.955.4572.

Lymphoma Research Foundation

The Lymphoma Research Foundation offers a Patient Aid Grant Program that provides limited financial assistance to lymphoma patients who are uninsured or have adequate medical insurance but struggle to pay for expenses related to their lymphoma treatment, such as medical bills, transportation costs to get to and from treatment, lodging expenses during treatment and childcare costs while they are at treatment. For more information, contact the Lymphoma Helpline at 800.500.9976 or visit www.lymphoma.org.

Patient Access Network Foundation

The Patient Access Network Foundation was formed to improve access to needed health services for insured patients who cannot afford the out-of-pocket costs associated with their treatment. In October 2004, the organization announced the launch of a new fund to meet the needs of patients diagnosed with cutaneous T-cell lymphoma. For more information, visit their website at www.panfoundation.org or call 866.316.7263.

Patient Advocate Foundation Co-Pay Relief Program

The Patient Advocate Foundation Co-Pay Relief Program provides direct financial support for pharmaceutical co-payments to insured patients, including Medicare Part D beneficiaries, who financially and medically qualify. For more information, visit www.copays.org or contact 866.512.3861.

Patient Services, Inc.

Patient Services, Inc. (PSI) offers a cutaneous T-cell lymphoma co-pay assistance program that is designed to help those eligible afford the cost of their expensive prescription medication (oral and topical). To apply, call a PSI customer service representative at 800.366.7741 or visit www.patientservicesinc.org.

GENERAL SUPPORT

American Cancer Society

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization. Headquartered in Atlanta, GA, the ACS has state divisions and more than 3,400 local offices. The national ACS mission statement says that the ACS is “dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy and service.” The ACS website provides information on all types of cancer, related resources and ACS programs. For more information, call 800.227.2345 or visit www.cancer.org.

Association of Cancer Online Resources

The Association of Cancer Online Resources (ACOR) hosts a large collection of free cancer-related Internet mailing lists and support communities. ACOR develops and hosts state-of-the-art Internet-

based knowledge systems that allow the public to find and use credible information relevant to their families. For more information, visit www.acor.org.

Cancer.Net (An ASCO Website)

ASCO's patient information website – Cancer.Net (www.cancer.net) – brings the expertise and resources of ASCO to people living with cancer and those who care for and care about them. Well-informed patients are their own best advocates and invaluable partners for physicians. Cancer.Net provides timely, comprehensive information to help patients and families make informed health care decisions. For more information, visit www.cancer.net or call 888.651.3038.

CancerCare

CancerCare is a national nonprofit organization that provides free, professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance. CancerCare has a variety of programs in place to assist those in need. For more information, visit www.cancercare.org or contact 800.813.HOPE (4673).

Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. The CSC is an international nonprofit dedicated to providing support, education and hope to people affected by cancer. Likely the largest employer of psychosocial oncology mental health professionals in the United States, CSC offers a menu of personalized services and education for all people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone. For more information, visit www.cancersupportcommunity.org or contact 888.793.9355.

Cancer Survivor Toolbox

The Cancer Survivor Toolbox® is a program of the National Coalition for Cancer Survivorship. The toolbox is a free audio program designed to help cancer survivors and caregivers develop practical skills to deal with the diagnosis, treatment and challenges of cancer. Transcripts of the program

are also available for reading if preferred. For more information, call 877.622.7937 or visit www.canceradvocacy.org/toolbox/.

CarePages

CarePages are free, personal, private web pages that help family and friends communicate when someone is receiving care. CarePages has partnered with Lotsa Helping Hands (listed on page 113) to provide friends, family, colleagues and neighbors with a system for coordinating their efforts to assist loved ones in need. For more information, visit www.carepages.com or call 888.852.5521.

CaringBridge

CaringBridge is a nonprofit organization offering free personalized websites to those wishing to stay in touch with family and friends during significant life events. Their mission is “to bring together a global community of care powered by the love of family and friends in an easy, accessible and private way.” CaringBridge authors can quickly and easily create personalized websites that display journal entries and photographs. Well-wishers visit the site to read updates and leave messages in the Guestbook. For more information, visit www.caringbridge.org or call 651.452.7940.

Fertile Hope

Fertile Hope is part of the LIVESTRONG organization and is dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility. For more information, visit www.fertilehope.org or call 855.220.7777.

Hope For Two...Pregnant With Cancer Network

The Pregnant With Cancer Network is a national nonprofit organization for women diagnosed with cancer during pregnancy. Their mission is to connect women who are pregnant with cancer with other women who are pregnant with the same type of cancer. For more information, call 800.743.4471 or visit www.pregnantwithcancer.org.

LIVESTRONG Foundation

LIVESTRONG Foundation is a nonprofit organization that provides support to guide people through the cancer experience, bring them together to fight cancer – and work for a world in which our fight is no longer necessary. They use the philosophy that “unity is strength,

knowledge is power and attitude is everything” and they provide practical tools and information to help the cancer community. For more information, call 855.220.7777 or visit www.livestrong.org.

Lotsa Helping Hands

Lotsa Helping Hands is a simple immediate way for friends, family, colleagues and neighbors to assist loved ones in need. Users can create a free, private web page and then invite family and friends to view a private group calendar specifically designed for organizing helpers. The aim is to facilitate everyone pitching in with the tasks necessary for life to run smoothly during a crisis such as delivery of meals, rides, babysitting and many others. For more information, visit www.lotsahelpinghands.com.

National Children's Cancer Society

For survivors of childhood cancers, the National Children's Cancer Society (NCCS) has created a program called Beyond The Cure. The mission of Beyond The Cure is to help childhood cancer survivors integrate the cancer experience into their new life as survivors and successfully handle the challenges that are ahead of them and to celebrate survivorship. For more information, visit www.beyondthecure.org or call 800.5.FAMILY (32-6459).

National Coalition for Cancer Survivorship

The National Coalition for Cancer Survivorship (NCCS) is the oldest survivor-led cancer advocacy organization in the U.S. and a highly respected authentic voice at the federal level, advocating for quality cancer care for all Americans and empowering cancer survivors. NCCS has also developed several programs with the goal of informing and empowering all those dealing with a cancer diagnosis through credible and accurate patient information. For more information, visit www.canceradvocacy.org or call 877.622.7937.

National LGBT Cancer Network

The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk by educating LGBT people and health providers about the cancer risks and survivor experiences of gay men, lesbians, bisexuals and transgender people; increasing awareness of LGBT cancer risks and survivor experiences; advocating for high quality research on LGBT cancer risks, treatment and survivorship; giving voice to LGBT cancer survivors; and offering consultation to healthcare providers. For more information, visit www.cancer-network.org.

National Organization for Rare Disorders

The National Organization for Rare Disorders (NORD), a nonprofit organization, is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. For more information, call 202.588.5700 or visit www.rarediseases.org.

Patient Advocate Foundation

The Patient Advocate Foundation is a national nonprofit organization whose mission is to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses. For more information, visit www.patientadvocate.org or contact 800.532.5274.

United Way of America

The United Way of America offers local toll-free information lines linking people to community resources and services such as emergency housing and food assistance. For more information and contact information on your local office, visit www.unitedway.org.

GOVERNMENT AGENCIES

ClinicalTrials.gov

The U.S. National Institutes of Health (NIH), through its National Library of Medicine (NLM), has developed this site in collaboration with the Food and Drug Administration (FDA). Clinicaltrials.gov offers up-to-date information for locating federally and privately supported clinical trials for a wide range of diseases and conditions. ClinicalTrials.gov contains tens of thousands of clinical studies sponsored by the National Institutes of Health, other federal agencies, and private industry. Studies listed in the database are conducted throughout the United States and in over 130 countries, and searches may be conducted by diagnosis, by sponsor or by recruitment status. ClinicalTrials.gov provides information about a trial’s purpose, who may participate, locations, and contact information to learn more details. In addition to providing listings, the website offers detailed information to help the reader understand how clinical trials are structured and governed. For more information, visit www.clinicaltrials.gov.

National Cancer Institute

The National Cancer Institute (NCI) is part of the National Institutes of Health (NIH), which is one of 11 agencies that compose the Department of Health and Human Services (HHS). The NCI, established under the National Cancer Institute Act of 1937, is the U.S. federal government’s principal agency for cancer research and training. The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. For more information, visit www.cancer.gov.

National Center for Complementary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) is the U.S. federal government’s lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. For more information, visit www.nccam.nih.gov.

National Institute of Arthritis and Musculoskeletal and Skin Diseases

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. For more information, visit www.niams.nih.gov.

National Institutes of Health

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the United States’ medical research agency—making important discoveries that improve health and save lives. The NIH is the largest source of funding for medical research in the world and is made up of 27 Institutes and Centers, each with a specific research agenda. For more information, visit www.nih.gov.

United States Department of Health and Human Services

The U.S. Department of Health and Human Services (HHS) is the U.S. federal government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. For more information, visit www.hhs.gov.

United States Social Security Administration

The U.S. Social Security Administration's mission is to deliver social security services that meet the changing needs of the public. The Administration delivers services through a nationwide network of over 1,400 offices that include regional offices, field offices, card centers, teleservice centers, processing centers, hearing offices, the Appeals Council, and their State and territorial partners, the Disability Determination Services. For more information, visit www.ssa.gov.

INSURANCE AND BENEFITS RESOURCES

BenefitsCheckUp

BenefitsCheckUp is a free service of the National Council on Aging, a nonprofit service and advocacy organization in Washington, DC. Many adults over 55 need help paying for prescription drugs, health care, utilities, and other basic needs. There are over 2,000 federal, state and private benefits programs available to help. But many people don't know these programs exist or how they can apply. BenefitsCheckUp asks a series of questions to help identify benefits that could save money and cover the costs of everyday expenses. For more information, call 202.479.1200 or visit www.benefitscheckup.org.

Department of Veterans Affairs

Eligible veterans and their dependents may receive cancer treatment at a Veterans Administration Medical Center. For more information, visit www.va.gov or call 877.222.8387.

Medicaid

Medicaid is a program supported by both federal and state funds in the U.S. and it is administered on the state level, meaning that eligibility guidelines and benefits available may differ considerably between states. Medicaid is intended to help individuals and families pay their medical expenses and eligibility is primarily based on income although certain factors such as age or disability may be considered. For more information

including contact information for your local Medicaid office, visit www.medicaid.gov.

Medicare

Medicare is a program supported by the U.S. federal government that provides health insurance for people over 65 years of age or people under 65 years of age with certain disabilities. For more information, visit www.medicare.gov.

State Health Insurance Assistance Program

The State Health Insurance Assistance Program (SHIP) is a national program that offers one-on-one counseling and assistance to people with Medicare and their families. Through federal grants directed to states, SHIP provides free counseling and assistance via telephone and face-to-face interactive sessions, public education presentations and programs, and media activities. For more information, visit www.shiptalk.org.

LEGAL RESOURCES

Cancer Legal Resource Center

The Cancer Legal Resource Center (CLRC) is a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles. The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, healthcare professionals, employers, and others coping with cancer. A cancer diagnosis may carry with it a variety of legal issues, including insurance coverage, employment and taking time off work, access to health care and government benefits, and estate planning. When these legal issues are not addressed, people may find that, although they have gotten through treatment, they have lost their homes, jobs, or insurance coverage. For more information, visit www.disabilityrightslegalcenter.org or call 866.843.2572.

MEDICAL PROFESSIONAL RESOURCES

International Society for Cutaneous Lymphoma

The International Society for Cutaneous Lymphomas (ISCL) is a worldwide professional association dedicated to the treatment, research and caring of patients with cutaneous lymphomas. The aim of the society is to increase knowledge of lymphomas of the skin, foster collaboration among clinicians and scientists around the world, and disseminate scientific information about diagnosis, management and treatment of cutaneous lymphoma. For more information, visit www.cutaneouslymphoma.org.

United States Cutaneous Lymphoma Consortium

The United States Cutaneous Lymphoma Consortium (USCLC) is a multidisciplinary professional organization dedicated to improving the quality of life and prognosis of patients with cutaneous lymphomas through discovery and application of new knowledge. The USCLC represents the only organization in America where professionals from various disciplines (dermatology, medical oncology, radiation oncology, and pathology) can exchange ideas and practice tips, discuss and plan scientific collaborations, develop new educational tools, and help shape the research agenda in cutaneous lymphoma. For more information, visit www.usclc.org.

MEDICATION ASSISTANCE

Allos Therapeutics (Folotyn®)

The Allos Therapeutics patient assistance program offers free medication to people who otherwise cannot afford their medications. Patients must meet financial and other program-specific criteria to be eligible for assistance. For more information, visit www.getasapinfo.com.

CancerCare Co-Payment Assistance Foundation

The CancerCare Co-Pay Assistance Foundation is a nonprofit organization established in 2007 to address the needs of individuals who cannot afford their insurance co-payments to cover the cost of medications for treating cancer. For more information, contact 866.55.COPAY (2-6729), 212.601.9750 or visit cancercarecopay.org.

Celgene Corporation (Istodax®)

Celgene Corporation, manufacturer of ISTODAX®, a drug used to treat cutaneous T-cell lymphoma and peripheral T-cell lymphoma, offers extensive patient support services through the Celgene Patient Support® program. This program provides a dedicated, central point of contact for patients and healthcare professionals who use Celgene products. The Celgene Patient Support® program is a free service that helps patients and healthcare professionals navigate the challenges of reimbursement, providing information about co-pay assistance, and answering questions about obtaining Celgene products. For assistance, call Celgene Patient Support® at 800.931.8691 or visit www.CelgenePatientSupport.com.

Chronic Disease Fund

The Chronic Disease Fund is an independent nonprofit charitable organization helping patients with chronic disease, cancers or life-altering conditions obtain the expensive medications they need. They assist patients throughout the United States who meet income qualification guidelines and/or have private insurance or a Medicare Part D plan but cannot afford the cost of their specialty therapeutics. For more information, visit www.cdfund.org or contact 877.968.7233.

Free Medicine Program

The Free Medicine Program offers free drugs. For more information, visit www.freemedicineprogram.com.

HealthWell Foundation

The HealthWell Foundation is a nonprofit organization committed to addressing the needs of individuals with insurance who cannot afford their copayments, coinsurance, and premiums for important medical treatments. Their vision is to ensure that no patient goes without health care because they cannot afford it. For more information, contact 800.675.8416 or visit www.healthwellfoundation.org.

Johnson & Johnson / Therakos (Photopheresis)

The Johnson & Johnson Patient Assistance Foundation, Inc. is a nonprofit organization that assists patients without adequate financial resources and prescription coverage obtain free products donated by Johnson & Johnson operating companies, including Therakos, the manufacturer of photopheresis, an approved immunotherapy for patients affected by cutaneous lymphoma. For more information, visit www.jjpaf.org or contact 800.652.6227.

Medicine Program

The Medicine Program is a patient advocate organization with a goal of assisting you and your family find, apply and qualify for the right patient assistance program(s) offered by pharmaceutical companies. By working closely with you, your doctor and the drug manufacturer, the Medicine Program helps cut through the red tape and assists you in receiving your medicine free of charge. Visit www.themedicineprogram.com for more information.

Merck (Zolinza®)

Sometimes, affording prescription medicines can be difficult. That's why Merck has created the Patient Assistance Program—to keep affordable medicines within your reach. This private and confidential program provides medicine free of charge to eligible individuals, primarily the uninsured who, without our assistance, could not afford needed Merck medicines. Individuals who don't meet the insurance criteria may still qualify for the Merck Patient Assistance Program if they attest that they have special circumstances of financial and medical hardship, and their income meets the program criteria. A single application may provide for up to one year of medicine free of charge to eligible individuals and an individual may reapply as many times as needed. For more information, visit www.merck.com/merckhelps/patientassistance/home.html or contact 800.727.5400.

National Organization for Rare Disorders

The National Organization for Rare Disorders (NORD) has a co-payment assistance program for people with peripheral T-cell lymphoma. For more information, visit www.rarediseases.org or call 202.588.5700.

NeedyMeds.org

NeedyMeds.org is a helpful resource to use for finding information about many drug assistance programs offered by states, localities and pharmaceutical manufacturers. Visit www.needymeds.org or contact 800-503-6897 for more information.

Partnership for Prescription Assistance

The Partnership for Prescription Assistance is a website hosted by pharmaceutical companies, physicians and patient advocacy groups that offers access to public and private patient assistance programs including more than 150 programs offered by pharmaceutical companies. For more information, visit www.pparx.org or contact 888.477.2669.

Patient Advocate Foundation Co-Pay Relief Program

The Patient Advocate Foundation Co-Pay Relief Program provides direct financial support for pharmaceutical co-payments to insured patients, including Medicare Part D beneficiaries, who financially and medically qualify. For more information, visit www.patientadvocate.org or contact 800.532.5274.

Patient Services, Inc.

Patient Services, Inc. (PSI) offers a cutaneous T-cell lymphoma co-pay assistance program that is designed to help those eligible afford the cost of their expensive prescription medication (oral and topical). To apply, call a PSI customer service representative at 800.366.7741 or visit www.patientservicesinc.org.

Pharmaceutical Research and Manufacturers of America

Some free or reduced-cost drugs are available through the Pharmaceutical Research and Manufacturers of America (PhRMA). Representing research-based pharmaceutical and biotechnology companies, PhRMA provides a Patient Assistance Directory on their web site, which is searchable by drug name or company. Visit www.phrma.org for more information.

Rx Outreach

RxOutreach has a number of very common generic drugs available at a low cost. Visit their website for a list of the drugs, application forms and other information about the program. For more information, contact 800.769.3880 or visit www.rxoutreach.com.

NUTRITION AND DIET RESOURCES

American Institute for Cancer Research

The American Institute for Cancer Research (AICR) is a nonprofit organization that fosters research on diet and cancer prevention and educates the public about the results. The AICR's website offers information and research on food, nutrition and cancer as well as suggested recipes. For more information, visit www.aicr.org or call 800.843.8114.

Office of Dietary Supplements

The mission of the Office of Dietary Supplements (ODS), within the National Institutes of Health, is to strengthen knowledge and understanding of dietary supplements by evaluating scientific information, stimulating and supporting research, disseminating research results, and educating the public to foster an enhanced quality of life and health for the U.S. population. For more information, visit <http://ods.od.nih.gov/> or call 301.435.2920.

PHYSICAL DISABILITY AND REHABILITATION RESOURCES

Disability.gov

Disability.gov is the United States' federal government website for comprehensive information on disability programs and services in communities nationwide. The site links to more than 14,000 resources from federal, state and local government agencies; academic institutions; and nonprofit organizations. You can find answers to questions about everything from Social Security benefits to employment to affordable and accessible housing. For more information, visit www.disability.gov.

RETREATS AND CAMPS

Camp Discovery

For young people with chronic skin conditions, Camp Discovery offers a summer camping experience unlike any they've had before. Every year, the American Academy of Dermatology sponsors a week of fishing, boating, swimming, water skiing, arts and crafts, and just plain fun. For more information, visit www.campdiscovery.org.

Camp Mak-A-Dream

One week can change a lifetime. This is the core belief at Camp Mak-A-Dream. The organization's mission is to provide a medically supervised, cost-free Montana experience, in an intimate community setting, for children, young adults and families affected by cancer. Retreats are offered for adult cancer survivors, young adults, kids and other groups. For more information, visit www.campdream.org or call 406.549.5987.

Healing Odyssey

Healing Odyssey is a nonprofit organization providing recovery and cancer support programs for cancer survivors. Their programs offer the practical tools, skills-building and support needed to cope effectively with the life-altering effects of a cancer diagnosis and treatment. For more information, visit www.healingodyssey.org or call 949.951.3930.

Stowe Weekend of Hope

The Stowe Weekend of Hope, through a partnership of Vermont's medical community and Stowe's hospitality businesses, offers an educational and inspirational retreat weekend for cancer survivors and their families. Through the various activities and educational offerings, cancer survivors

and their families are given an opportunity to gather with members of the medical community and with others in order to further their understanding of the disease affecting their lives. The goal of the Stowe Weekend of Hope is to provide this enriching experience without the financial burden. Each year, Stowe lodge/hotel owners donate hundreds of free rooms to cancer survivors and their loved ones, so the lodging and retreat are free (attendees incur meal expenses only). For more information, call 800.GO.STOWE (467.8693) or visit www.stoweohope.org.

SCHOLARSHIP SUPPORT

Cancer Survivors' Fund

Cancer Survivors' Fund is a nonprofit organization that provides college scholarships and prosthetics for the benefit of persons diagnosed with cancer, receiving treatment for cancer or in remission to give them a new purpose and meaning in life. For more information, visit www.cancersurvivorsfund.org.

National Collegiate Cancer Foundation

The National Collegiate Cancer Foundation's mission is to provide services and support to young adults who have been diagnosed with cancer. The Foundation's goal is to help these survivors and their families establish a "Will Win" attitude in their fight. For more information, visit www.collegiatecancer.org.

Patient Advocate Foundation "Scholarships for Survivors" Program

The purpose of the Patient Advocate Foundation's "Scholarship for Survivors" program is to provide scholarships to individuals, under the age of 25, who have been diagnosed with or treated for cancer and/or a chronic/life threatening disease within the past 5 years. For more information, visit www.patientadvocate.org/index.php?p=69 or call 800.532.5274.

The Ryan Mullaly Second Chance Fund

The Ryan Mullaly Second Chance Fund is a nonprofit organization offering scholarship assistance to young people who are fighting lymphoma. The organization looks for young men and women whose high school years were disrupted by lymphoma and whose ability to qualify for most scholarships was precluded by the extensive absenteeism and physical disabilities which result from chemotherapy and radiation. For more information, visit www.ryans2dchancefund.org.

SAMFund

The SAMFund is a unique nonprofit organization created to assist young adult survivors of cancer with a successful transition into their post-treatment life by providing financial support through the distribution of grants and scholarships. For more information, visit www.thesamfund.org or call 617.938.3484.

Ulman Cancer Fund for Young Adults

The Ulman Cancer Fund for Young Adults is committed to helping young adults continue their education after being affected by cancer through their own diagnosis or the diagnosis of a loved one. For more information, visit www.ulmanfund.org or call 888.393.FUND (3863).

SELF-IMAGE RESOURCES

Look Good...Feel Better

Look Good...Feel Better is a free, non-medical, brand-neutral, national public service program that helps women offset appearance-related changes from cancer treatment. For more information, call 800.395.LOOK (5665) or visit www.lookgoodfeelbetter.org.

Shop Well With You

Shop Well With You (SWWY) is a not-for-profit organization and body-image resource for women surviving cancer, their caregivers and healthcare providers. Through its website, SWWY focuses on helping women improve their self-image and quality of life. For more information, visit www.shopwellwithyou.org.

Where There's A Need

Where There's A Need is a nonprofit organization that provides support and encouragement for women and children with cancer. The organization designs and creates unique head garments, which address many appearance-related concerns. For more information, call 866.803.6095 or visit www.wheretheresaneed.org.

TRANSPORTATION ASSISTANCE

American Cancer Society's Road to Recovery

Every day thousands of cancer patients need a ride to treatment, but some may not have a way to get there. The American Cancer Society's Road to Recovery program provides transportation to and from treatment for

people who have cancer who do not have a ride or are unable to drive themselves. Volunteer drivers donate their time and the use of their cars so that patients can receive the life-saving treatments they need. For more information, visit www.cancer.org/Treatment/SupportProgramsServices/road-to-recovery or call 800.227.2345.

Lymphoma Research Foundation

The Lymphoma Research Foundation T-Cell Lymphoma Transportation Assistance Fund grant program provides financial assistance to T-cell lymphoma patients (including those with forms of cutaneous T-cell lymphoma) who are uninsured or have adequate medical insurance but struggle to pay for transportation costs (e.g., mileage, parking, tolls, gas, train tickets, etc.) to get to and from treatment. Grants in the amount of \$500 will be awarded and applicants can re-apply every 6 months for a total maximum annual award of \$1,000. Applicants must: 1) Complete an application and demonstrate financial need; and 2) Be currently undergoing T-cell lymphoma treatment as certified by their physician. For more information, visit www.lymphoma.org or call the Lymphoma Helpline at 800.500.9976.

TRAVEL AND LODGING

Air Care Alliance

Air Care Alliance is a nationwide league of humanitarian flying organizations whose volunteer pilots are dedicated to community service. When there is financial need, private pilots volunteer their time to transport patients to necessary treatments. For more information, contact 888.260.9707, 918.745.0384 or visit www.aircareall.org.

Corporate Angel Network

Through the generosity of many large corporations, the Corporate Angel Network fills empty seats on corporate jets with cancer patients in need of travel assistance. Eligibility to participate is open to all cancer patients, bone marrow donors and bone marrow recipients who are ambulatory and not in need of medical support while traveling. Eligibility is not based on financial need and patients may travel as often as necessary. For more information, visit www.corpangelnetwork.org, email info@corpangelnetwork.org or contact 866.328.1313.

Angel Flight

Angel Flight arranges free air transportation in response to health care and other compelling human needs. For more information, contact 918.749.8992 or visit www.angelflight.com.

Hope Lodge

Facing cancer is hard. Having to travel out of town for treatment can make it even harder. Yet the American Cancer Society has a place where cancer patients and their caregivers can find help and hope when home is far away - an American Cancer Society Hope Lodge. Each Hope Lodge offers cancer patients and their caregivers a free, temporary place to stay when their best hope for effective treatment may be in another city. Not having to worry about where to stay or how to pay for lodging allows guests to focus on getting well. Hope Lodge provides a nurturing, home-like environment where guests can retreat to private rooms or connect with others. Every Hope Lodge also offers a variety of resources and information about cancer and how best to fight the disease. For more information, visit www.cancer.org/treatment/supportprogramsservices/hopelodge/index or call 800.227.2345

Joe's House

Joe's House is an online nationwide lodging resource for cancer patients and their families who must travel away from home for medical treatment. Their website lists cancer treatment centers and hospitals across the country with nearby lodging facilities that offer a discount. Visit www.joeshouse.org for more information.

National Association of Hospital Hospitality Houses, Inc.

The National Association of Hospital Hospitality Houses, Inc. is a nationwide professional association of nearly 200 unique, nonprofit organizations that provide lodging and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities. For more information, visit www.nahhh.org or call 800.542.9730.

National Patient Travel Center

The purpose of the National Patient Travel Center is to ensure that no financially-needy patient is denied access to distant specialized medical evaluation, diagnosis or treatment for lack of a means of long-distance medical air transportation. Their National Patient Travel HELPLINE

is a free service that provides information about all forms of charitable, long-distance medical air transportation providing referrals to all appropriate sources of help available in the national charitable medical air transportation network. For more information, contact 800.296.1217, visit www.patienttravel.org, or email info@nationalpatienttravelcenter.org.

WORKPLACE SUPPORT

www.cancerandcareers.org

This website provides an online forum filled with information intended for the working woman with cancer. Their philosophy is "Worklife doesn't stop once you've been diagnosed with cancer." Many women have to – and want to – work during and after treatment. This website offers information and tools "to help working women manage their battle with cancer as effectively as they manage the rest of their lives."

YOUNG ADULTS RESOURCES

I'm Too Young For This! Cancer Foundation

Stupid Cancer (aka: I'm Too Young For This! Cancer Foundation) is a nonprofit organization that empowers young adults affected by cancer through innovative and award-winning programs and services. This Foundation is the largest support community in the United States for this underserved population and serves as a bullhorn for the young adult cancer movement. For more information, visit www.stupidcancer.com or call 877.735.4673.

SAMFund

The SAMFund is a unique nonprofit organization created to assist young adult survivors of cancer with a successful transition into their post-treatment life by providing financial support through the distribution of grants and scholarships. For more information, visit www.thesamfund.org or call 617.780.9606.

Ulman Cancer Fund for Young Adults

A leading voice in the young adult cancer movement, the Ulman Cancer Fund for Young Adults is working at a grassroots level to support, educate, connect and empower young adult cancer survivors. The organization works at both the community level and with our national partners to raise awareness of the young adult cancer issue and ensure all young adults and

families impacted by cancer have a voice and the resources necessary to thrive. For more information, visit www.ulmanfund.org or call 888.393.FUND (3863).

Please note that the organizational information and resources listed in this section are accurate and available based on information known at the time of publication of this guide.

Please refer to our website for
additional and updated information.

www.clfoundation.org

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How to Get Involved and Give Back

There are many ways to get involved and help support the Cutaneous Lymphoma Foundation in our efforts to make sure that each person with cutaneous lymphoma gets the best care possible. We encourage involvement from passionate individuals, corporate partners and community organizations who want to join in our work. There are many opportunities to become engaged including:

Share Your Story

Sharing your story is a fantastic way for you to help others who are traveling down the same path that you are - whether you are a patient, caregiver, healthcare provider or a supporter. Patients and others who read our newsletter or visit our website often tell us that one of their favorite features are the stories of the lives of people who are affected by cutaneous lymphoma. Contact us at info@clfoundation.org or 248.644.9014 if you would like to share your story.

Become An Advocate

Becoming an advocate for people affected by cutaneous lymphoma is a very important way that you can become involved in supporting patients with cutaneous lymphoma.

You can participate by visiting the Advocacy section of our website at www.clfoundation.org/Advocacy often to monitor advocacy news and action alerts that you can participate in. We also invite you to contact us at info@clfoundation.org or 248.644.9014 if you are interested in our advocacy efforts.

Become A Donor

Becoming a donor to the Cutaneous Lymphoma Foundation by giving to our Annual Fund Campaign or participating in other fundraising events, is one of the most important ways that you can help support our work.

Our Annual Fund Campaign provides vital unrestricted funding we need throughout the year for all of our programs and services. This campaign

supports every patient, every caregiver, every healthcare provider and any other person who calls upon us for assistance. You can make a gift any time online at www.clfoundation.org/giving-online, via phone at 248.644.9014 or by using the form at the back of this guide to send in your donation.

Organize A Fundraiser

Organizing a fundraiser to benefit the Foundation or an awareness event is a great way to support our mission. Your efforts help build significant awareness for cutaneous lymphoma in addition to raising funds to support our programs and services. Event organizers and fundraisers range from individuals to families to companies and community groups. For more information about organizing a fundraiser, visit www.clfoundation.org or phone us at 248.644.9014.

Volunteer

At the Foundation, we have specific projects or tasks that arise for which we need volunteer help. If you are interested in volunteering, send us an email at info@elfoundation.org for more information or call 248.644.9014.

To learn more about how you can get involved and give back, visit the **GET INVOLVED** and **WAYS TO GIVE** sections of our website at www.clfoundation.org.

Notes



www.clfoundation.org