

Cutaneous Lymphoma Foundation Strategic Plan 2012-2015



Making sure each person with cutaneous lymphoma gets the best care possible

Our Mission

The mission of the Cutaneous Lymphoma Foundation is to support 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.

Contents

3	Overview
4	About the Cutaneous Lymphoma Foundation
5	Organizational Structure
6	What Is Cutaneous Lymphoma?
7	Programs and Services
8	Major Accomplishments
9	Mission, Vision and Values
10	Strategic Planning Approach
11-16	Strategic Goals
17	Board of Directors and Staff

Overview

In June 2011, the Cutaneous Lymphoma Foundation set forth a mandate to create a Strategic Plan for the Foundation's future based on these themes:

- First and foremost, we work passionately to make sure that each person with cutaneous lymphoma gets the best care possible.
- We engage and support the world's leading physicians, scientists and researchers to improve cutaneous lymphoma treatment and accelerate finding a cure.
- We represent people with cutaneous lymphoma and all people affected by the disease ensuring that their voices are heard in our communities and our government.
- We unleash the talents and resources of people touched by cutaneous lymphoma, encouraging new ideas and celebrating progress from every source and every effort.
- We ask for support boldly.

This mandate was set forth because the themes above reflect the expectations that have been expressed by people with cutaneous lymphoma, their family members, physicians, researchers, clinicians, donors, volunteer leaders and staff about the role of the Cutaneous Lymphoma Foundation.

On behalf of the patients and all stakeholders who are invested in our mission, it is truly an honor to bring forward this visionary blueprint for implementation by thousands of individuals and corporate, foundation and organizational partners who work together to advance our mission.

The pages that follow include the following Strategic Plan components: mission; vision; values; and strategic goals and objectives.

The **mission** defines the fundamental purpose of the Foundation describing why we exist. The **vision** defines the intended future state of the Foundation. The **values** of the Foundation are deeply-held driving forces behind the Foundation's activities and will guide behaviors toward all of our stakeholders.

The **strategic goals and objectives represent** a framework developed from our mission, vision and values that outlines priority goals for the Foundation. It describes how we, the duly elected volunteer and staff leaders, will respond to the opportunities and threats that we encounter in our efforts to fulfill our mission. Goals and objectives included in this plan are challenging and aggressive, while still being achievable within a 3-year period from July 2012 – June 2015.

This Strategic Plan honors the history of the Foundation, deepens its current areas of focus, demands new focus on vital areas of organizational, programmatic and financial growth, and it positions the Foundation to reach greater levels of excellence in service to all of our stakeholders.

Together, we will accomplish these goals delivering life-changing outcomes for patients and others affected by cutaneous lymphoma throughout the world.

Sincerely,



Stuart R. Lessin, MD
Board President



Jennifer A. Viano
Chief Executive Officer

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.

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.

Organizational Structure

At present in April 2012, the Cutaneous Lymphoma Foundation is governed by 10 members of the Board of Directors comprised of individuals who have a diverse array of expertise, knowledge, skills and capabilities. Patients, medical professionals and others with a strong passion and commitment to our mission populate the Foundation's Board.

Various Foundation committees are primarily led by board members who serve on these committees to advance areas of the Foundation's work including advocacy, board governance, development, finance, medical affairs, and programs and services.

The Foundation's Medical Advisory Board is comprised of 18 of the world's top cutaneous lymphoma specialists who meet annually and work in partnership with the Foundation on matters specifically related to patient treatment and care and medical research.

The Foundation's staff includes 4 full-time employees (CEO, Director of Operations and Finance, Director of Development, and Administrative Assistant) and one full-time consultant who works on programs and services.

Significant progress on the Foundation's work is achieved by passionate, dedicated, talented volunteers who help in many ways – through ambassadorship at events, committee involvement, holding fundraisers and assisting with special projects, our volunteers are vital partners in advancing our mission.

What Is Cutaneous Lymphoma?

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based on lymphocyte type: B-lymphocytes (B-cell) or T-lymphocytes (T-cell).

Cutaneous T-cell lymphoma (CTCL) is the most common type of cutaneous lymphoma that typically presents with red, scaly patches or thickened plaques of skin that often mimic eczema or chronic dermatitis. Progression from limited skin involvement is variable and may be accompanied by tumor formation, ulceration, and exfoliation, complicated by itching and infections. Advanced stages are defined by involvement of lymph nodes, peripheral blood, and internal organs.

Cutaneous lymphomas affect thousands of individuals worldwide. CTCL affects over 30,000 people in the United States and Canada. The incidence of cutaneous T-cell lymphoma in the United States is increasing with approximately 3,000 new cases being diagnosed annually. Due to the difficulty of diagnosing the disease in its early stages and the current lack of an accurate reporting system, prevalence of cutaneous lymphoma is thought to be much higher.

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 experts in the field, and connect with other people who share in 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

The Foundation offers a variety of printed and electronic educational resources including our new *Patient's Guide to Understanding Cutaneous Lymphoma*, fact sheets, brochures, 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 otherwise, 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 established a new Research Awards Program, the first 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.

Advocacy

At the Cutaneous Lymphoma Foundation, we advocate on behalf of people affected by cutaneous lymphoma 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.

Major Accomplishments

- 1996 CTCL-MF Listserv, an online support group, established for patients to share experiences.
- 1998 The Mycosis Fungoides Foundation incorporated and begins serving patients, caregivers and others affected by cutaneous lymphoma worldwide. The Foundation hires its first employee, a Director of Patient Education.
- 1999 The Foundation launches its website at www.mffoundation.org. The Foundation establishes its Medical Advisory Board.
- 2004 The Foundation hires a Director of Operations and Finance.
- 2005 The Foundation is renamed the Cutaneous Lymphoma Foundation and expands its mission.
- 2007 The Foundation funds its first research study, *Incidence of Cutaneous T-Cell Lymphoma in the United States, 1973-2002*, which was conducted by Drs. Vincent Criscione and Martin Weinstock of Brown University and published in the July 2007 issue of the *Archives of Dermatology*.
- 2009 The Foundation holds a very successful Cutaneous Lymphoma Summit in New York City where education, clinical care and research priorities are identified.
- 2010 The Foundation publishes Proceedings from its 2009 Cutaneous Lymphoma Summit.
The Foundation hires a CEO and Director of Programs and Services.
- 2011 The Foundation expands Board of Directors with six new members.
The Foundation re-launches its website at www.cclfoundation.org with a comprehensive re-design and new content.
- 2012 The Foundation adopts new 3-year Strategic Plan for fiscal years 2012-2015.
The Foundation hires a Director of Development and Administrative Assistant.
The Foundation establishes new Research Awards Program, the first dedicated exclusively to funding cutaneous lymphoma research.

Mission

The mission of the Cutaneous Lymphoma Foundation is to support every person with cutaneous lymphoma by promoting awareness and education, advancing patient care and facilitating research.

Vision

As the recognized leader worldwide in providing cutaneous lymphoma resources, we will eliminate the burden of cutaneous lymphomas and improve the quality of patient lives; create research opportunities to improve therapy; and promote activities leading to the discovery of a cure.

Values

The organizational values governing the Cutaneous Lymphoma Foundation are:

Integrity, Honesty, Trust, Respect and Equality

The Foundation is committed to operating with integrity, honesty, trust, respect and equality. We adhere to high ethical and professional standards in our work and in behaviors that define our relationships. We are fair and respectful in our interactions and conscientiously steward the resources entrusted to us.

Independence

The Foundation is an independent nonprofit patient advocacy organization that is guided in its work by its own set of values and ethical standards. We do not allow relationships with outside entities, including funders, influence how decisions are made about how we deliver programs and services to our patients or how we conduct any Foundation business.

Leadership

The Foundation is led by talented, knowledgeable, dedicated and inspirational individuals who are passionate about our mission and who work diligently to accomplish the organization's goals.

Impact

The Foundation is committed to making a positive and life-changing impact on the lives of the people it serves. We listen and understand the needs of our patients and all stakeholders and use a collaborative approach with those we serve to make the greatest and most positive impact we can on their lives.

Excellence

In all that we do, we are committed to employing best practices and achieving overall organizational excellence.

Compassion and Commitment to Care

The Foundation shows compassion in its work with a commitment to care in the delivery of our programs and services and in collaborations with partners in our mission.

Teamwork

The Foundation is dedicated to the advancement of our mission through the collaborative efforts and effective, enthusiastic involvement of all stakeholders.

Continual Improvement

The Foundation accepts responsibility and accountability for ongoing improvement of the quality of the organization's operations, programs and services and overall development.

Strategic Planning Approach

The approach to developing the 2012-2015 Cutaneous Lymphoma Foundation Strategic Plan was structured by the Foundation's Board of Directors with particular focus on ensuring that key constituencies were involved in the process. Patients, caregivers, medical professionals, supporters and other strategic partners were consulted during the process and specific feedback was solicited from these constituencies through a comprehensive strategic planning survey.

The internal development process included the following activities:

Phase 1

At its meeting in June 2011, the Foundation's Board of Directors initiated the process by discussing the vision for the future of the Foundation, the need for a Strategic Plan, and development approaches. After this meeting, a strategic planning consultant was engaged to begin formal work on creating the plan.

Phase 2

During the period of August 2011 – January 2012, a strategic planning survey was developed and sent to key stakeholders including the Foundation's Board of Directors, staff, patients, caregivers, medical professionals, supporters and other partners in the Foundation's mission. Feedback was gathered on stakeholders' impressions and recommendations related to the Foundation's mission, vision, strengths, weaknesses, opportunities, threats, proposed goals and objectives, and top priorities.

Phase 3

During the period of January – March 2012, Foundation staff worked closely with the strategic planning consultant to develop a draft Strategic Plan, taking into consideration data presented in the Strategic Planning Survey Report, which included all responses provided by stakeholders through the survey.

Phase 4

In advance of the meeting of the Foundation's Board of Directors in March 2012, the draft Strategic Plan was circulated to board members for their review. At the March 2012 board meeting, a dedicated strategic planning session was held and facilitated by the strategic planning consultant. During this session, board members and staff discussed the draft plan in detail, recommended and incorporated updates to refine the plan, and the final 2012-2015 Cutaneous Lymphoma Foundation Strategic Plan was adopted.

An operational plan will be used to monitor progress on the metrics and proposed outcomes related to the strategic goals and objectives.

The 2012-2015 Strategic Plan will be formally reviewed and updated annually by the Foundation's Board of Directors to ensure it is brought current to meet the Foundation's evolving strategic issues and priorities.

Strategic Goal One

Advance patient care through education and support to address the challenges of each person whose life is affected by a diagnosis of cutaneous lymphoma.

This goal is fundamental to the reason why the Cutaneous Lymphoma Foundation exists: To make sure that each person with cutaneous lymphoma gets the best care possible.

Following are objectives that will support achievement of Goal One:

Objective One: Provide and enhance education programs.

Key initiatives related to this objective include:

- Improving content on the Foundation's website at www.clfoundation.org
- Improving content in the Foundation's printed newsletter, *Forum*
- Publishing a new *Patient's Guide to Understanding Cutaneous Lymphoma*
- Improving the Foundation's Patient Educational Forums
- Continuing to enhance educational opportunities for patients through partnerships with other complementary organizations such as the Lymphoma Research Foundation, The Leukemia & Lymphoma Society, *CancerCare* and others
- Improving education through better use of technology
- Improving education provided to patients in other countries

Objective Two: Provide and enhance support programs.

Key initiatives related to this objective include:

- Continuing and enhancing personal support provided via phone and email
- Improving access to patient assistance programs including those for financial, medication, legal, travel and other forms of assistance
- Enhancing access to in-person support groups
- Continuing and enhancing the facilitation of referrals needed by patients for cutaneous lymphoma treatment centers and patients

Strategic Goal Two

Sustain the Foundation to ensure current and long-term viability.

To ensure that the Cutaneous Lymphoma Foundation exists for cutaneous lymphoma patients now and for years to come – as well as making sure that the Foundation is able to continually provide high-quality programs for patients that deliver life-changing, positive outcomes – this goal is essential.

Following are objectives that will support achievement of Goal Two:

Objective One: Grow annual revenue.

Key initiatives related to this objective include:

- Growing unrestricted support
- Growing the number of the Foundation's annual donors
- Growing and diversifying corporate support
- Growing support from third party fundraisers
- Growing planned giving support

Objective Two: Improve the Foundation's development infrastructure.

Key initiatives related to this objective include:

- Conducting a development audit
- Creating and implementing a new development plan

Objective Three: Support professional development for the Foundation's staff.

Key initiatives related to this objective include:

- Conducting annual reviews of staff
- Providing opportunities for professional development for staff

Objective Four: Optimize the Foundation's operational infrastructure.

Key initiatives related to this objective include:

- Using industry best practices, enhance the Foundation's operational infrastructure
- Utilizing the Foundation's database in a more comprehensive, effective and powerful way to collect and use data
- Establishing and implementing evaluation procedures to record, analyze, and report outcomes achieved for patients and others through delivery of programs

Strategic Goal Three

Promote awareness to increase knowledge and understanding about cutaneous lymphoma and the Cutaneous Lymphoma Foundation.

Because cutaneous lymphoma is a rare disease, not many people know what cutaneous lymphoma is or its signs and symptoms – including medical professionals such as community dermatologists and primary care physicians who are oftentimes the first physicians who initially treat and work to diagnose patients. The Cutaneous Lymphoma Foundation is also not known and utilized to its potential to help patients, caregivers, medical professionals and others.

The Foundation is committed to improving awareness with key constituencies who need to have a better understanding of the disease and the resources available at the Foundation to ultimately help get more help get patients properly diagnosed, treated and supported throughout their journey.

Following are objectives that will support achievement of Goal Three:

Objective One: Provide and enhance patient awareness.

Key initiatives related to this objective include:

- Providing news and information via the Foundation's ongoing e-newsletters
- Providing news and information via social media platforms including the Foundation's Facebook page
- Launching a new blog

Objective Two: Provide and enhance public awareness.

Key initiatives related to this objective include:

- Providing news and information via the Foundation's ongoing e-newsletters
- Providing news and information via social media platforms including the Foundation's Facebook page
- Launching a new blog

Objective Three: Raise the medical community's awareness.

Key initiatives related to this objective include:

- Increasing awareness of the Foundation with cutaneous lymphoma specialists and treatment centers
- Attending annual medical meetings including the American Academy of Dermatology, the American Society of Hematology, the Dermatology Nurses' Association and others
- Partnering with complementary medical professional organizations such as the United States Cutaneous Lymphoma Consortium and the International Society for Cutaneous Lymphomas
- Increasing awareness of cutaneous lymphoma with community dermatologists, oncologists, primary care physicians and physician assistants
- Establishing educational programs for dermatology and oncology nurses
- Improving website resources for medical professionals
- Securing placement of cutaneous lymphoma-specific articles in peer-reviewed journals for dermatologists, oncologists, physician assistants and nurses

Strategic Goal Four

Facilitate research for improved treatment and for a cure for cutaneous lymphoma.

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, though, we still only have a hint as to the origins of cutaneous lymphomas. The Cutaneous Lymphoma Foundation is committed to facilitating and funding research in cutaneous lymphoma to help understand more about its causes, improve treatments and, ultimately, find a cure.

Following are objectives that will support achievement of Goal Four:

Objective One: Raise awareness about the need for cutaneous lymphoma research.

A key initiative related to this objective is:

- Launching a robust and sustained research awareness campaign

Objective Two: Develop a sustainable cutaneous lymphoma Research Awards Program.

A key initiative related to this objective is:

- Launching a new Research Awards Program, the first dedicated exclusively to funding cutaneous lymphoma research, that supports research priorities identified in cutaneous lymphoma

Objective Three: Advocate for increased multidisciplinary research.

A key initiative related to this objective is:

- Creating and implementing a plan for increased multidisciplinary research funding from the National Institutes of Health

Strategic Goal Five

Advocate for people affected by cutaneous lymphoma.

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 more. The Foundation works to make sure that the patient's voice is heard in our communities and in our government.

Following are objectives that will support achievement of Goal Five:

Objective One: Advocate for greater access to cutaneous lymphoma treatments.

A key initiative related to this objective is:

- Developing a position statement and implementing a plan for health insurance inclusion and reimbursement of all cutaneous lymphoma treatments listed in national treatment guidelines

Objective Two: Advocate for changing the term "mycosis fungoides" to "Alibert Lymphoma" in lymphoma classification schemas.

A key initiative related to this objective is:

- Developing a position statement and advocating for this change with relevant stakeholders

Objective Three: Collaborate with partner organizations to advocate for issues of mutual benefit.

A key initiative related to this objective is:

- Continuing participation in relevant advocacy initiatives and events sponsored by partner organizations including the National Institutes of Health, the Food & Drug Administration, the National Organization for Rare Disorders, and others

Objective Four: Advocate multidisciplinary care as the standard of care for cutaneous lymphoma.

A key initiative related to this objective is:

- Developing a position statement and advocating for multidisciplinary care as the standard of care for cutaneous lymphoma with relevant stakeholders

Strategic Goal Six

Recruit and mobilize the talents and resources of people committed to advancing the mission of the Cutaneous Lymphoma Foundation.

Engaging people who are passionate about our work at the Cutaneous Lymphoma Foundation is critical to ensuring the achievement of the Foundation's goals. So many people -- patients, caregivers, loved ones, medical professionals, supporters, organizational partners and others -- give generously of their time, talent and treasure to advance our mission and serve patients.

Following are objectives that will support achievement of Goal Six:

Objective One: Cultivate the productivity of the Foundation's Board of Directors.

Key initiatives related to this objective include:

- Conducting a board assessment resulting in a board action plan
- Creating an updated board composition analysis to help guide future recruiting efforts
- Recruiting new board members who best match identified profiles needed to further develop a highly-effective, exceptional Board of Directors

Objective Two: Optimize the role of the Medical Advisory Board.

A key initiative related to this objective is:

- Creating and implementing a plan to optimize the Medical Advisory Board

Objective Three: Establish an Advisory Council.

A key initiative related to this objective is:

- Creating and implementing a plan for establishment and recruitment of individuals to a new Advisory Council

Objective Four: Build a volunteer program.

Key initiatives related to this objective include:

- Creating and implementing a plan to build a volunteer program
- Recognizing the Foundation's most involved volunteers

Board Of Directors and Staff

Officers

Stuart R. Lessin, M.D.
President

Marianne Tawa, RN, MSN, ANP
Vice President

Jeff Ward
Treasurer

Laurel Carlson
Secretary

Directors

Joseph Eischens

Brace Krag

David Lamb

Pierluigi Porcu, M.D.

Christopher Shipp

Michael Young

Jennifer A. Viano

Staff

Kira Mann
Director of Development

Holly Priebe
Director of Operations and Finance

Debra Van Zegeren
Administrative Assistant

Jennifer A. Viano
Chief Executive Officer

Cutaneous Lymphoma Foundation

PO Box 374
Birmingham, MI 48012
Phone: 248.644.9014
Fax: 248.644.9014
Email: info@clfoundation.org
Web: www.clfoundation.org