



**CUTANEOUS  
LYMPHOMA  
FOUNDATION**

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## **Volunteer Manual**

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## Welcome

Dear Volunteer,

Welcome to the Cutaneous Lymphoma Foundation! Thank you for your time, energy and interest in volunteering for the Cutaneous Lymphoma Foundation! Simply put the work that we do cannot be done without the efforts of our volunteers. Your time is valuable so this manual was developed to help introduce you to the Cutaneous Lymphoma Foundation. Everything you need to know in order to get started is included in this book. If you have any questions as you read through, don't hesitate to let us know.

We are excited to have you join us in making a difference for all people touched by cutaneous lymphoma.

Thank you,

Susan Thornton  
Chief Executive Officer

## Our History

The Mycosis Fungoides Foundation originated from one feeling -- frustration.

When Judy Jones was diagnosed with cutaneous T-cell lymphoma (CTCL) in 1990, she went from feeling that her world was falling apart to learning to live with the disease. Her search for information to help her with this journey turned quickly to frustration -- she had never heard of CTCL, knew no one else with CTCL, and could find no information. Judy wondered how other people were coping with a disease about which they knew nothing. In 1996, she created and went on-line with the CTCL-MF information/support listserv. The listserv grew fast as the word got out, as the Internet increased in size and people became computer literate.

Meanwhile, Judith Shea's husband, Lee Allen Cohen, was diagnosed with Sézary syndrome in 1994 and passed away in 1996. Once again frustration abounded. 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 information and support to others with cutaneous lymphoma diseases. Mr. Cohen's physician was Dr. Stuart Lessin, a dermatologist treating cutaneous lymphoma patients in Philadelphia, and Judith met with him several times to discuss ways to reach her goal.

In 1999 Dr. Lessin was also frustrated. He felt that a patient advocacy group could call attention to the needs for education and research in this field. After receiving information about the on-line cutaneous lymphoma information/support listserv from one of his patients, he called Judy Jones and suggested that she consider starting a foundation. Remembering Judith's goals, he also called her to discuss the idea of a foundation for mycosis fungoides patients. Dr. Lessin then suggested that the two "Judys" talk and consider attending the upcoming American Academy of Dermatology (AAD) meeting to assess the support of other physicians. During the AAD meeting, they met with the International Society of Cutaneous Lymphoma (ISCL) and other patient advocacy groups and determined that yes -- this foundation was needed.

Using the funds from the Lee Allen Cohen memorial as seed money, a foundation was created. Frustration found its purpose: The Mycosis Fungoides Foundation.

In 2005, the Board of Directors changed the name to the Cutaneous Lymphoma Foundation to include all types of cutaneous lymphomas.

## About the Cutaneous Lymphoma Foundation

### What is the Cutaneous Lymphoma Foundation (CLF)?

The CLF is an independent, non-profit patient advocacy organization dedicated to supporting all people affected by cutaneous lymphomas by promoting awareness and education, advancing patient care, and facilitating research.

### What does the Cutaneous Lymphoma Foundation do?

The CLF provides programs and services that provide disease, treatment and quality of life information both in live events, through online and written communications. The Foundation also advocates and raises awareness about this rare group of diseases on behalf of all people affected by cutaneous lymphoma regarding access, reimbursement and treatment issues with policy makers around the world. Research initiatives are another cornerstone to the programs offered by the CLF through the Research Award program and Young Investigator award programs.

### What DOESN'T the Cutaneous Lymphoma Foundation do?

The CLF does not recommend medical treatments and are not a substitute for the expertise of medical professionals.

### How is the Foundation funded?

Funding comes from multiple sources. Grants are received from industry organizations along with donations from individuals and fundraising events. All effort is made to balance the funding sources in order to maintain financial stability to support the ongoing delivery of the programs and services.

### Whom do we serve?

All people affected by cutaneous lymphoma; patients, caregivers, medical professionals and others impacted in some way by the disease.

## Current and Ongoing Projects

### Live Events (CLF)

#### ➤ Patient Education Forum (PEF):

Patient Education Forums (PEF) are a one-day program designed to provide people affected with cutaneous lymphoma education, support and an ability to network with others. These programs are held throughout the United States with the occasional event in Canada, Europe or another location with a strong patient population and treatment facility.

#### ➤ Answers From the Experts - Live (AFTE):

Answers From the Experts - Live (AFTE) programs are an evening program designed to provide people affected with cutaneous lymphoma an opportunity to get support, have questions answered by cutaneous lymphoma specialists and communicate with others living with cutaneous lymphoma. These programs are held throughout the United States.

#### ➤ 2-Day Patient Educational Conference:

The 2-Day Patient Education Conference is a program is two days and designed to provide education, support and the ability to network with others. The 2-day program spans a wide range of topics from clinical presentations delivered by experts to quality of life topics like nutrition. This expanded format also provides opportunities for small group breakout discussions and time for peer-to-peer networking.

### Networking Groups

Networking groups were developed to allow people affected by cutaneous lymphoma a place to come together for networking and to support one another. On occasion a speaker or activity will be offered as part of a meeting to add variety and/or an educational opportunity. These groups also participate in fundraising initiatives as well as raising awareness. The current locations are as follows:

Washington, DC  
Portland, OR  
Salt Lake City, UT  
Las Vegas, NV  
New York, NY

### Partner Programs

The Cutaneous Lymphoma Foundation participates in and collaborates with its partner organizations to expand our reach and meet our mission of supporting all people impacted by cutaneous lymphoma. We include our partners' programs on our website and list them in our Forum Newsletter and eNews email blasts. A CLF representative, when possible, attends their event and will be provided a table to display literature, and may participate and speak in any cutaneous lymphoma sessions.

- Lymphoma Research Foundation
- Leukemia and Lymphoma Society
- Triage Cancer
- T-Cell Leukemia & Lymphoma Foundation (TCLLF)

## Publications

### ➤ eNews

The eNews is a monthly email blast scheduled to be distributed on the 1st business day of each month. Its purpose is to highlight current topics and events in and around the cutaneous lymphoma community. Articles are sent to, gathered and managed by the Information Technology Manager. Monthly, these articles, along with any current CLF activities are pulled together to create the eNews. Once the eNews is emailed, it is also uploaded to social media to extend its reach.

### ➤ Forum Newsletters

The Forum Newsletter is a publication distributed three times a year, and is anywhere from 12 - 16 pages in length. Each issue is designed to address a different focus regarding cutaneous lymphoma; Issue 1 - Research in cutaneous lymphoma, Issue 2 - Patient-Centered Care, and Issue 3 - Awareness and Engagement. The article contributors are compiled across our constituency in an effort to bring multiple perspectives and a balanced publication.

### ➤ A Patient's Guide to Understand Cutaneous Lymphoma

The Patient's Guide was designed to provide people affected by cutaneous lymphoma one comprehensive book to address a wide variety of issues. This book is provided to anyone who requests copies free of charge upon request. To ensure accuracy, the clinical content is written by, continually reviewed and periodically updated by experts in cutaneous lymphoma. The publication is scheduled to be reviewed every two years and revised as necessary.

### ➤ Treatment Supplement

The Treatment Supplement is a comprehensive listing of the current cutaneous lymphoma treatments. To ensure accuracy, the clinical content is written by, continually reviewed and periodically updated by experts in cutaneous lymphoma. The publication is scheduled to be reviewed every year and revised as necessary.

### ➤ Fast Fact Brochures

The Fast Facts brochures and sheets provide people with a one-page document addressing the specific variant diagnosis. To ensure accuracy, the clinical content is written by, continually reviewed and periodically updated by experts in cutaneous lymphoma. These documents are scheduled to be reviewed every two years and are revised as necessary. Listed below are our current topics.

- Cutaneous T-Cell Lymphoma – Mycosis Fungoides (CTCT – MF)
- Lymphoid Papulosis (LyP)
- Cutaneous B-Cell (CBCL)
- Sézary Syndrome

### ➤ Research Report

The Research Report is an annual publication focused on the research or researchers supported by the Cutaneous Lymphoma Foundation. The Research Report is the

responsibility of the research program manager and is due to be completed and circulated annually in late February. Contributors include the Chair of the Research Advisory Council (RAC), researchers (past and present). This publication is intended to be clinical in nature and focused on the efforts of our clinical community.

### **Webcast - Live Streaming**

Webcasts of our Patient Educational Forums and 2-Day Patient Conferences are provided to allow people affected by cutaneous lymphoma the ability to virtually attend and participate in the Foundation's in-person programs. These events are streamed through our YouTube channel and live as a recording on the channel upon the conclusion of the program.

### **Facebook - Live - Variant Specific Programs**

Facebook - Live events were developed to focus education and awareness toward specific variants of cutaneous lymphoma. Through the use of Facebook, CLF hosts live virtual events and educational information targeted through the corresponding Facebook pages. The topics addressed in the programs will correspond with the group's page and focus on the issues they are facing.

### **Website**

#### **➤ Online Learning Center**

The Online Learning Center (OLC) is a section of the website addressing topics faced by people affected by cutaneous lymphoma. This section of the site was developed to be a place where people could learn about their disease by topic (quality of life, treatment options, diagnosis, etc.) or by disease variant (mycosis fungoides, Sézary Syndrome, B-Cell, etc.). The OLC is populated with medical professional articles, videos and what's in the news.

### **Advocacy and Awareness**

Throughout the year the CLF participates in various activities and initiatives to bring awareness about cutaneous lymphoma and the CLF to members of its community, as well as the general public. These efforts are throughout the United States and on occasion in Canada and other countries. The initiatives include material distribution, participating in activities in both the nation's and states' capitals and participating and encouraging others to participate in designated awareness days.

### **Facilitating Research**

The CLF promotes biomedical research in cutaneous lymphoma through its strategic partnerships with medical and scientific research organizations, clinical investigators, and professional societies.

We support research by:

- Promoting scientific exchange
- Developing new careers in cutaneous lymphoma research
- Supporting investigator-initiated research

## **Thank you for joining the Cutaneous Lymphoma Foundation team!**

Upon your decision to join the Cutaneous Lymphoma Foundation Volunteer Team, we will set up a time to meet with you either virtually or in person to better get to know you. At this time, we can be sure you have all the tools you need to join the Cutaneous Lymphoma Foundation.

## **EXPECTATIONS**

### **What You Can Expect From Us**

- We want to foster an environment of openness and community with our volunteers. We want our volunteers to feel important and appreciated.
- We ask for feedback from our volunteers on their experience at regular intervals through surveys. We appreciate honest input from our volunteers.
- We offer a variety of volunteer opportunities. If you would like to switch, or to participate in multiple efforts, just ask.
- All proper orientations and training will be provided free of charge to our volunteers. We will give you all the tools necessary to properly perform any assigned tasks.
- We will inform you regularly about any changes in schedules or locations of events.
- Volunteers do not generally replace the paid staff of the Cutaneous Lymphoma Foundation. They do, however, offer assistance that allows us to provide services more effectively and efficiently.
- Periodically, we will review your progress, as well as offer and ask for suggestions for improvement.

### **What We Expect From Our Volunteers**

The relationship between an organization and its volunteers is an organic, ever-changing entity. While we do try to provide a relaxed, open environment, certain policies must be implemented and enforced. As a volunteer for our organization, you are our public face. Anything you do while volunteering is a reflection of Cutaneous Lymphoma Foundation and our communities in general.

Our volunteers commit:

- To perform all tasks to the best of their abilities, skills and level of responsibility.
- To actively seek guidance from staff to improve performance.
- To work within all assignments time.
- To maintain accurate records of volunteered time.
- To dress in a fashion that is appropriate to the tasks required.
- To demonstrate a considerate, amicable appearance to the public, other volunteers and our staff.
- To promote a safe working environment and report any hazards to the volunteer supervisor.
- To respect facilities, equipment and other property at the various venues where we do our work.
- To work effectively in a team environment.
- To represent the Cutaneous Lymphoma Foundation in a professional manner at all times.

## Policies

### Definition of Commonly Used Terms:

Cutaneous Lymphoma Foundation .....	CLF or the Foundation
Chief Executive Officer .....	CEO
Chief Operating and Financial Officer .....	COFO

### Recognition

The primary rewards of volunteering one's time are not physical in nature. The majority of volunteers offer their time because they want to contribute to a cause greater than themselves. Volunteering promotes a heightened sense of self and community, and offers opportunities for personal growth.

However, it is important that individuals and groups be recognized for their efforts. All Cutaneous Lymphoma Foundation volunteers will be recognized throughout the year through our outreach and social media.

### Communication

Communication is an important part of any relationship, be it personal or professional. We hope to foster an environment where our volunteers feel comfortable enough to come to us with any ideas about how to improve the program.

If you have anything you wish to discuss with us, or if you wish to express a complaint, please let the volunteer supervisor know and we will do our best to accommodate you.

Also, we ask you to keep us posted if you have a situation that will prevent you from attending an event, be it transportation problems, illnesses or scheduling conflicts. Please let us know as soon as you can about any extenuating circumstances.

### Identification

We hope that you will be proud to be identified as a volunteer with the Cutaneous Lymphoma Foundation! When volunteering at an event you will be provided with and expected to wear a name badge that includes a volunteer ribbon.

### Volunteers Under the Age of 18

All volunteers under the age of 18 will be required to submit a parental permission waiver for volunteers under the Age of 18 form prior to volunteer.

### Time Tracking and Reporting

Each volunteer will keep accurate track of time spent performing tasks for CLF and will report their time via email to their volunteer supervisor at the end of each day. Time worked can be rounded to the nearest quarter hour. Time submitting should include dates, hours worked, and the activities undertaken.

## **Absenteeism**

We depend upon our volunteers for the success of an event. Please inform your volunteer supervisor if there is an emergency or illness that will prevent you from participating in an event you have signed up for. If there is continued absenteeism of more than two events - a CLF staff member will meet with you to discuss your volunteer position on our team.

## **Grievance Procedure**

If as a volunteer, you find yourself in a situation that you feel a CLF staff member needs to assist on, please contact your volunteer supervisor so that they can solve the issue in a timely manner. If your volunteer supervisor is the person that you feel you need assistance with, please contact either the CLF CEO or COFO.

## **Code of Ethics**

Every volunteer represents the Cutaneous Lymphoma Foundation to the public. We ask all of our volunteers to recognize that they are the face of CLF and to act in a manner that is professional and thoughtful when in their role. We depend upon the community's trust and confidence and require volunteers to act with integrity and honesty. Please dress in a manner that is appropriate for your work steering clear of clothes that are torn, frayed, or revealing.

## **Confidentiality**

Each volunteer with the Cutaneous Lymphoma Foundation may have opportunity to interact with members of the community and each volunteer must protect this relationship. Our volunteers may never, under any circumstance, disclose the personal information of our donors, our database, or workshop participants. For example, when working on a CLF event, collect personal information only as much as is reasonable for the purposes. Ensure that the personal information is correct and then protected by getting the information into the hands of a CLF staff member.

## **Equal Opportunity/Qualifications**

The most important qualifications to becoming a volunteer are the willingness to serve, an open mind and a love of our cutaneous lymphoma community.

All volunteers are protected under Federal Equal Employment Opportunity Laws. The Cutaneous Lymphoma Foundation affords equal opportunity without regard to race, color, sex, religion, age, marital status, disability, veteran status, sexual orientation, ethnic origin or nationality.

However, we may require prospective volunteers to provide a personal reference, who will be contacted. Certain assignments could warrant a background check, with the volunteer's permission.

## **The Americans with Disabilities Act**

The Americans with Disabilities Act (ADA) requires employers to reasonably accommodate qualified individuals with disabilities.

It is the Cutaneous Lymphoma Foundation's policy to comply with all federal and state laws concerning the employment of persons with disabilities as well as volunteers. It is our policy not to discriminate against qualified individuals with disabilities in regard to any aspect of the volunteer selection, orientation, or training process. CLF reasonably accommodate qualified volunteers with a disability so that they can perform the essential functions of their volunteer assignment.

If there is the case beyond our control, we will attempt to find a volunteer role that can ensure any person can participate with CLF that desires.

## **Sexual Harassment**

Sex-related harassment in the workplace is sex discrimination and, as such, is prohibited by Title VII of the 1964 Civil Rights Act. The CLF regards such behavior, whether verbal or physical, as a violation of the standards of conduct required of all persons associated with this organization.

The CLF prohibits any form of sexual harassment. Anyone inflicting such behavior on others is subject to disciplinary action. Sexually harassing conduct in the workplace, whether committed by supervisors or non-supervisory personnel is prohibited. This includes: repeated offensive sexual flirtations or advances; continual or repeated verbal abuse of a sexual nature; sexually degrading words used to describe an individual; and the display in the workplace of sexually suggestive objects or pictures.

Complaints of sexual harassment should be brought to the attention of the Chief Executive Officer. Such complaints will be investigated confidentially and impartially and will be resolved promptly.

## **Marketing and Outreach**

CLF will produce all marketing, outreach and/or materials for distribution to ensure all materials are in line with the Foundation's branding and message.

### **➤ Printed Materials:**

CLF will produce any necessary marketing, outreach and/or printed materials as long as they are budgeted for and approved.

➤ **Branding:**

Any materials voluntarily produced on behalf of the CLF must be pre-approved prior to their use. When creating outreach announcements only non-altered CLF logos and branding will be accepted whether they are in print, online or for social media.

➤ **Social Media and External Communication:**

As volunteers for the CLF, you are not authorized to comment or speak on behalf of the CLF in any communications. Only CLF staff and specific members of the Board of Directors are authorized to make statements or speak on behalf of the CLF. When posting to social media sites or other external communication vehicles, make sure you only post information about the activities and refrain from providing any additional comments that might be your personal opinion. If you are interacting from your personal perspective, it must be clear that you are doing so. If communicating as a volunteer, it is imperative you follow the requests/rules of the site's administrators.

## **Counseling**

➤ **Providing Guidance and/or Counseling:**

Under no circumstances are volunteers permitted to provide a patient or caregiver with medical advice regarding their diagnosis and/or treatment. It is best to always refer any patient or caregiver to their physician and/or to a Foundation employee for further assistance. It is acceptable to share a personal experience and/or story to provide support, provided it is not intended to be a recommendation for their approach to their diagnosis and/or disease.

## **Reimbursement Policy**

Expenses incurred that are wholly, exclusively, and necessarily on behalf of the foundation and have been preapproved, should be submitted to the Chief Operating and Financial Officer of the CLF for reimbursement by the organization.

### **Reimbursement Procedure**

Travel on behalf of the CLF requires pre-approval using the Travel Request Form prior to making travel arrangements. The CLF Reimbursement Form is to be used for requesting reimbursement and should be submitted within three weeks of completion of the trip or other approved expenditure and explanations should be provided for all unusual items or amounts. Any expense in question will be reviewed and decided upon by the COFO. Receipts are required for all expenditures, including credit card charges, airfare, travel agent, and applicable hotel charges. Receipts are required for all expenditures paid by the traveler. Please allow at least two weeks after receipt at the CLF for reimbursement.

➤ **Non-Reimbursable Expenditures**

- First-class upgrades in air travel (this does not preclude the use of free class upgrades).
- When lodging accommodations have been arranged by the CLF and the traveler elects to stay elsewhere, reimbursement is made at an amount no higher than the rate negotiated by the CLF, and reimbursement is not made for transportation between the alternate lodging and meeting site.
- If an individual accompanies the traveler, it is the responsibility of the traveler to determine the added cost for double occupancy and related expenses and to make the appropriate adjustment in the reimbursement request.
- Entertainment costs including movies, liquor, or bar costs.

## Volunteer Manual Acknowledgement Form



I certify that I have received and read the Cutaneous Lymphoma Foundation's Volunteer Manual Policy. I understand the purpose of the manual and its included policies and agree to adhere to the policies to protect the integrity of the mission and operations of the Cutaneous Lymphoma Foundation.

**Printed Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix A

### Alphabet Soup: A guide to terms and acronyms used at CLF

**AAD:** American Academy of Dermatology

**ASH:** American Society of Hematology

**BOD:** Board of Directors

**CARRA:** Consumer Advocates in Research and Related Activities

**CDC:** Centers for Disease Control and Prevention

**CLIP:** Cutaneous Lymphoma Information Project

**CTCL:** Cutaneous T-Cell Lymphoma

**EORTC:** European Organization for Research and Treatment of Cancer

**ESRD:** European Society for Dermatologic Research

**IID:** International Investigative Dermatology

**ISCL:** International Society for Cutaneous Lymphoma

**JSID:** Japanese Society for Investigative Dermatology

**LRF:** Lymphoma Research Foundation

**LyP:** Lymphomatoid Papulosis

**MF:** Mycosis Fungoides

**NCI:** National Cancer Institute

**NDRI:** National Development & Research Institutes

**NIAMS:** National Institute of Arthritis and Musculoskeletal and Skin Diseases

**NIH:** National Institutes of Health

**NORD:** National Organization of Rare Diseases

**PUVA:** PUVA is a 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.

**SID:** Society of Investigative Dermatology

**UVB:** Narrow Band UVB is a form of UVB phototherapy that concentrates ultraviolet output into a narrow range. It can be an effective treatment for patch-stage mycosis fungoides as well as other skin diseases. Broad Band UVB is term that refers to the type of phototherapy that uses the entire UVB range including the sun burning rays of ultraviolet light.

## Reimbursement Form

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Please list your expenses:

Hotel \_\_\_\_\_

Airfare \_\_\_\_\_

Ground Transportation:

Car Rental \_\_\_\_\_

Train \_\_\_\_\_

Taxi \_\_\_\_\_

Mileage (if applicable)

\_\_\_\_\_ @ current Federal reimbursement rate = \_\_\_\_\_

Parking/Tolls \_\_\_\_\_

Miscellaneous \_\_\_\_\_

TOTAL \_\_\_\_\_

Signature \_\_\_\_\_

Note: Please read carefully

- All expense items require a receipt (MapQuest map or similar for Mileage)
- Forward this expense reimbursement form within two weeks of meeting for reimbursement to:

Holly Priebe, [holly@clfoundation.org](mailto:holly@clfoundation.org)

or

Holly Priebe  
Cutaneous Lymphoma Foundation  
PO Box 374  
Birmingham, MI 48012



**CUTANEOUS LYMPHOMA FOUNDATION**

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