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.

What is Cutaneous Lymphoma?

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based upon 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.
Letter from the President of the Board and the Chief Executive Officer

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

For close to fifteen years this has been the mission of the Cutaneous Lymphoma Foundation. During this time, the Foundation has continued to grow and expand its programs and services to meet the continuous challenges faced by the patients and families we serve. In 2011-2012, the Foundation enjoyed one of its most successful years with the additions of new programs that reach across the globe.

The publication and launch of A Patient’s Guide to Understanding Cutaneous Lymphoma was distributed in more than 40 countries, providing patients with a comprehensive resource when dealing with cutaneous lymphoma. We increased the volume of the patient voice by joining with other coalitions to advocate for improved healthcare and rare disease research in Washington, DC. Most exciting, we established the framework for research funding specific to cutaneous lymphoma and established a 3-year strategic plan to support continued growth in years to come.

The year has seen the Cutaneous Lymphoma Foundation grow in numbers as we’ve added talent to our Board of Directors and office staff. The addition of Joseph Eischens, Esq., as a new board member expands the range of professional expertise of the Board. As a patient himself, Joe brings a unique perspective to help guide and direct the Foundation. New staff members in the area of development and office management enable the Foundation to be more responsive to patients and their families’ needs, expand our programs and services, and fulfill the mission more effectively and efficiently.

At the core of our mission is the support of patients. The Cutaneous Lymphoma Foundation has supported patients in 17 live programs across the United States and Canada, updated the website to allow for easier navigation and more effective access to patient and caregiver resources and provided support to hundreds of patients and caregivers through our phone support program.

Serving patients and their families is impossible without the continued generosity of so many who join us each year to fulfill our mission. It is through the support of our patients, caregivers, board of directors, medical professionals and corporate partners that we have been able to continue to assist those impacted by cutaneous lymphoma and provide the community of support they need on their journey with this rare disease. Whether it is through financial support or gifts of time and talent, each and every person has a profound impact on the success of the foundation.

As we look to next year, we look forward to continuing to serve those who need us most by providing the knowledge and resources related to treatment, quality of life and ensure that patients are armed with as much information as possible to make knowledgeable and informed treatment decisions along with their medical team. Exciting programs and services are in the wings that will enable the CLF to touch more patients and support research for a cure.

Each day, as we fight against this rare disease and all of its challenges, the staff and board of directors of the foundation will always remember that there is an individual behind the disease who looks to us to provide support, sound information and hope. With each step forward, we continue to dedicate our efforts to serving all patients living with cutaneous lymphoma.

TOGETHER WE MAKE A DIFFERENCE!

Stuart Lessin, M.D.
President

Susan Thornton
Chief Executive Officer
I’ve learned as much about my inner strengths as I have about my medical condition since being diagnosed with cutaneous T-cell lymphoma in 2009. I now know about bouncing back from physical and emotional challenges, about the value of support from family and friends, and about how sharing experiences helps other patients.

A big lesson is that there’s nothing remarkable about any of this. I’m not better-equipped than anyone else. We all adapt to situations that arise.

Before my diagnosis in 2009, I went through a year and a half of searching for answers. A puffy rash first appeared on one side of my face in 2008 and after several months of trying various topical creams prescribed by a dermatologist, a biopsy was finally sent out for analysis. It took four days to get the results, which came via cell phone late on a Friday afternoon in September 2009, right before my 31st birthday. That was the first time I heard about a type of cancer called CTCL. I was alarmed, naturally. No family member had cancer or a skin condition. I was diagnosed with a rare variant – folliculotropic CTCL – that doesn’t fit the usual profile.

As I searched for more information on this rare disease, I found the Cutaneous Lymphoma Foundation. The foundation website provided the details for which I was searching. Further understanding and reassurance came as treatment began at the University of Pittsburgh Medical Center. I was lucky to have such a great center for CTCL treatment and research at the same university where I happen to teach political science.

At age 33, I’m far younger than most patients – as was clear when I joined a support group at the hospital and again when I attended my first Patient Educational Forum hosted by the Foundation. Initially I felt out of place as I listened to other patients in their 60s and 70s speak of living with our disease. By the end of the forum I felt more at ease as the other patients listened and provided support as I shared my journey with this rare disease. Now that I have attended multiple Cutaneous Lymphoma Foundation-sponsored forums they have become a fantastic community where as patients we can all share our struggles, joys, and journey together.

Thanks to my medical team and the Cutaneous Lymphoma Foundation, I have optimism and a sense of community. What I accept is that honesty beats self-pity, and that putting one foot in front of the other is the only way through any rough journey. When you’re in it, you just do it. Resilience displaces regret because it must.

“What I accept is honesty beats self-pity, and that putting one foot in front of the other is the only way through any rough journey.”
Living With Cutaneous Lymphoma: A Caregiver's Story

Meredith Haab
Wayne, PA

I'd like to share my Mom with you: She was a huge smile, an infectious laugh, a flirt, and she sparkled. She was fun, eccentric, often outrageous, and was hugely generous. She was full of life and lived gracefully even as she faced living with cancer, CTCL, Cutaneous T-Cell Lymphoma.

My Mom was young at heart. She was an artist with a free and creative spirit. She drove carriages, was a national floral design judge and award winning flower arranger. She invented and patented needlepoint stitches and yet most importantly to her, she was a wife, mother, and grandmother. She rocked us for hours and sang to us when we were sick. She baked cookies with us, organized our making Christmas gifts for Grandparents and teachers, orchestrated amazing birthday parties and holiday dinners, drove us everywhere, stood by us in hard times, and rejoiced with us during good times.

At the age of 68, Mom developed what we first thought were hives and then later were told was psoriasis. She suffered stoically for years with the itching and peeling skin. Then a lesion developed on her leg. Our worst fear was realized: Mom had cutaneous lymphoma. She was in late stage two. Mom started treatments but progressed unusually rapidly through each one. This wasn't going the way we had hoped. Our lives were changing quickly. We were scared and felt alone. No one we knew had heard of this cancer. No one talked about it. No one could share miraculous recovery stories or personal self-care suggestions. This wasn’t a well-known cancer, and now I know: this doesn’t have the funding of a well-known cancer.

One day at work, the school librarian came rushing in to tell me to go online and look at the Cutaneous Lymphoma Foundation website that she had found for me. She was excited and I was stunned: There was information, there were contacts. There were answers to our questions. Suddenly, we had a community and resources. Finally, we were not alone.

The Cutaneous Lymphoma Foundation was there to support my family during what was the most difficult time my family has ever faced. I am grateful for the support we received and to the instant community of families and patients we now belonged to who understood the struggles we faced day to day.

The pain of losing my Mom to such a difficult and rare disease has led to action: I work closely with the Foundation by sharing what I learned about lesion care as my mother’s caregiver, to help others care for their loved ones. My husband is involved by helping the Foundation with the new patient registry program. We heal and honor my Mom by helping others as the Foundation helped us when we needed it most.

“There was information, there were contacts. There were answers to our questions. Suddenly, we had a community and resources. Finally, we were not alone.”

Meredith Haab
Wayne, PA
2011 - 2012 Highlights

During the past fiscal year (July 1, 2011– June 30, 2012), the Cutaneous Lymphoma Foundation accomplished much progress on many fronts including:

- Serving over 650 patients and caregivers through holding eight Patient Educational Forums and collaborating in nine affiliated educational events in 17 cities throughout the United States and in Canada.

- Connecting with 1000+ individual patients through one-to-one support services and/or filling requests for literature.

- Completion of the needs assessment survey.

- Completion of a strategic plan to support the growth of the Foundation for years to come.

- Increased participation with collaborative groups:
  - Coalition of Skin Diseases
  - Lymphoma Coalition
  - Canadian Patient Skin Alliance

- Increasing the CLF staff by adding a director of development and an office manager.
• Increasing cutaneous lymphoma awareness in the medical community by attending the following medical meetings:
  o American Society of Hematology
  o American Academy of Dermatology
  o American Society of Clinical Oncologists
  o Society of Investigative Dermatology
  o Dermatology Nurses Association
  o T-Cell Forum

• Increasing the visibility and needs of those affected by CTCL to lawmakers through advocacy in Washington, DC, including:
  o One Voice Against Cancer
  o Rare Disease Day 2012
  o FDA’s Inaugural Patient Network Annual Meeting
  o Coalition of Skin Diseases Lobby on the Hill

• Publishing and distributing over 9000 copies of “A Patient’s Guide to Understanding Cutaneous Lymphoma” to patients, caregivers and medical professionals worldwide.
Statement of Financial Position • Year Ending June 30, 2012

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>2012</th>
<th>2011</th>
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<tbody>
<tr>
<td>Cash and cash equivalents</td>
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<td>Investments</td>
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<td>Promises to give</td>
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<td>Security deposit</td>
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<td>Furniture</td>
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<td><strong>Total assets</strong></td>
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<th>LIABILITIES AND NET ASSETS</th>
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<td>Accounts payable</td>
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<td><strong>Total liabilities</strong></td>
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<td>Net Assets</td>
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<td>Unrestricted</td>
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<td>621,524</td>
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<tr>
<td><strong>Total net assets</strong></td>
<td><strong>$1,125,478</strong></td>
<td><strong>$1,282,273</strong></td>
</tr>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td><strong>$1,156,575</strong></td>
<td><strong>$1,301,903</strong></td>
</tr>
</tbody>
</table>

Statement of Activities • Year Ended June 30, 2012

<table>
<thead>
<tr>
<th>Support and Revenue:</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
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<tbody>
<tr>
<td>Contributions and grants</td>
<td>191,432</td>
<td>245,100</td>
<td>436,532</td>
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<td>Merchandise sales, net of cost of goods sold of $144</td>
<td>6</td>
<td>-</td>
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<td>Investment income</td>
<td>3,822</td>
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<td>3,822</td>
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<td><strong>Total support and revenue</strong></td>
<td><strong>$195,260</strong></td>
<td><strong>$245,100</strong></td>
<td><strong>440,360</strong></td>
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</tbody>
</table>

| Net Assets Released from Temporary Restrictions | $250,500 | ($250,500) | - |
| **$445,760** | **($4,400)** | **$440,360** |

<table>
<thead>
<tr>
<th>Functional Expenses:</th>
<th>Unrestricted</th>
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<th>Total</th>
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</thead>
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<td>458,836</td>
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<td>Management and general</td>
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<td>Fundraising</td>
<td>50,065</td>
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<td>50,065</td>
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<tr>
<td><strong>Total functional expenses</strong></td>
<td><strong>$597,155</strong></td>
<td><strong>-</strong></td>
<td><strong>$597,155</strong></td>
</tr>
</tbody>
</table>

| Change in Net Assets | (151,395) | (5,400) | (156,795) |
| Net Assets - Beginning | 660,749 | 621,524 | 1,282,273 |
| Net Assets - Ending | $509,354 | $616,124 | $1,125,478 |

Expense Ratio

The Foundation’s programs expense ratio in fiscal year 2012 was approximately 77 percent. These funds were used to deliver vital programs and services including Patient Educational Forums, our website, teleconferences, educational newsletters and e-newsletters, personal assistance, advocacy and research efforts, and much more.
The Cutaneous Lymphoma Foundation is deeply grateful to all of the donors who supported our mission through financial contributions during our 2011-2012 fiscal year (July 1, 2011 - June 30, 2012). Your gifts have enabled us to make sure each person with cutaneous lymphoma receives the best care possible and that the Foundation can continue to expand our programs and services to support those who need us most. Thank you for your support.

**Recognition Society Donors**

Beginning with our 2010-2011 fiscal year, we created new recognition societies in conjunction with our Annual Fund Campaign that provide leadership donors with benefits that include special recognition in our annual report. We are pleased to acknowledge these donors below.

**Visionary of Care Society**  
$10,000+ Annual Fund Campaign Giving

- Celgene Corporation
- Ceptaris Therapeutics, Inc
- Eisai, Inc
- Merck & Co., Inc
- Therakos, Inc.

**Partner in Care Society**  
$5,000 - $9,999 Annual Fund Campaign Giving

- Kathy Bromage
- Seattle Genetics
- Suzanne Gylfe
- Najafi Companies, LLC
- Florence Seligman

**Friend in Care Society**  
$1,000 - $4,999 Annual Fund Campaign Giving

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- Direct Brands, Inc.
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- Jennifer Kirby-Chaffin
- Kenneth Kobarg
- Dr. Stuart and Karen Lessin
- Chris and Melody Malachowsky
- Greg Ostrowski
- Mark Rusley
- Patrick Ryan
- Robert Shipp
- Sara Smith
- United Way of King County
- Jennifer Viano
- John Webb
- Michael Yang
AllDonors

The following list includes all individual, corporate and foundation donors who contributed to our Annual Fund Campaign or supported other programs and services.

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Dr. Sunil Abhyankar  
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Dr. Kevin D. Cooper  
David Copelin

“Go through whatever you have to face. Don’t sit in one spot and worry about what is ahead. It’s like sitting in a rocking chair - you use up energy but you haven’t gone anywhere...

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John Barnett  
Daniel Barolsky  
Dr. Geraldine T. Merola Barton  
Anna Bartow  
Elizabeth Bassan  
H. L. Bauer  

...You don’t know what lies ahead so take that energy and use it to fight today’s battle. Deal with the problems as they come to pass...

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- Suzanne M. Gyfle
- Deberah Haferkamp
- Roberta Hamovitz
- Phyllis Handelsman
- Nancy Hanson
- Emogene Hanvey

...Don’t add the burden of worry to the mix. You need all your strength to fight this cancer.”

Terry, Pittsburgh, PA

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- Eisai, Inc
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- Seattle Genetics
- Therakos
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Seymour Putterman
Myrna W. Pyke
Amelia Ransom Letcher
Walther Rapchinski, Jr.
Barbara Rauch
Lenore Rauch
Rob Rawnsley
Patricia Ray
Diane Raynes
Dan Reed
Elaine Reinbold Pitkin
Joy Reliford
Diana Remick
Grace Renna

Toronto Patient Educational Forum

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Megan Reynolds
Permar and Nancy Richards, III
Dr. Betty Richmond
Daniel and Carol Ritting
Richard Rivard
Rita Roach
Thelma Roach
William Robins
Nancy Rocamora
Richard G. and Joan B. Rocamora
Ann Marie and Michael Rocce
Cheryl Romine
Gary Rose
Jane A. Rossi
Maria Rossi
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### Accuracy Statement

The report recognizes contributions received by the Cutaneous Lymphoma Foundation July 1, 2011 through June 30, 2012. Please accept our apologies if we have made any errors or omissions with your name or gift. If your listing requires correction, we apologize and ask you to contact us at info@clfoundation.org or 248.644.9014.
Looking Ahead

As we look ahead to what the Cutaneous Lymphoma Foundation hopes to accomplish in the coming fiscal year, there is much to be excited about:

- Increased patient programming including the first 2-day Patient Educational Forum to be held in Philadelphia, June 29-30, 2013.

- The creation and launch of our online learning center - a central location where individuals can quickly and easily find information they need about cutaneous lymphoma. As the center grows, we will add new features including video, podcasts, blogs, interactive media versions of our materials, online patient/caregiver support communities and more.

- The launch of the CLARIONS research grant program. CLARIONS stands for Curing Cutaneous Lymphoma by Advancing Research, Innovation and Offering New Solutions. This signature funding initiative of the Foundation’s Research Awards Program (RAP), supports investigators conducting innovative cutaneous lymphoma research. These grants will help uncover causes of and improve the treatment of CTCL and quality of life for patients. Key goals are discovering new avenues for better therapies today and one day, a cure for cutaneous lymphoma.

- Partnering with the Global Rare Diseases Patient Registry and Data Repository (GRDR) pilot project. The Cutaneous Lymphoma Foundation was chosen to participate as one of only 24 patient advocacy organizations in the registry program which is sponsored by the National Institutes of Health Office of Rare Diseases. This project will enable us to create an online global patient registry, fulfilling a longtime goal of the Foundation. The registry will store de-identified patient data which will be organized in a standardized manner enabling the study of many rare diseases and facilitating research projects, clinical studies, and clinical trials. The aim of the global registry is to assist in drug and therapeutic development, and to improve the quality of life for the many millions of people who are suffering from rare diseases.

- Updating and revising patient materials to reflect new cutaneous lymphoma and treatment information. This will include the publishing of supplements to the *A Patient’s Guide to Understanding Cutaneous Lymphoma*.

- Revising the website to improve the users’ experience and ease in finding the information they need.

We rely on the foundation for information that enables us to get the best care for my husband. The foundation’s tireless efforts to create a network of support for those diagnosed with this disease - as well as a forum for the world’s top CTCL doctors to collaborate - gives us hope that we will find a cure before too long!

Amy, Concord, NH