

ANNUAL REPORT

Fiscal Year 2018



Celebrating 20 Years of Service and Support to the Community



**CUTANEOUS
LYMPHOMA
FOUNDATION**

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.

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20 Years of Service and Support...



1996 - Judy Jones created the CTCL ListServe; providing patients with an online community.



1998 - The **Mycosis Fungoides Foundation** was established, incorporated and received non-profit status early the following year.

Approximately 1999 - *Mycosis Fungoides Fast Facts*, our first disease-specific pamphlet with basic information for new patients and their families, was published, distributed and made available to physicians' offices nationwide.

FROM THE CHIEF EXECUTIVE OFFICER



Susan Thornton

Thomas Jefferson is quoted as saying "I like the dreams of the future better than the history of the past".

Couldn't agree more - AND - I am proud to be celebrating the 20th year of the Cutaneous Lymphoma Foundation in 2018. What began 20 years ago as a deep desire to connect with others who were facing a similar diagnosis, has led to a global, interconnected community dedicated to empowering anyone impacted by a diagnosis of cutaneous lymphoma.

This year we served people around the world by bringing educational programs to everyone in our community using technology. Facebook live monthly interviews and live streaming of our educational events provided individuals with opportunities to speak with and connect to physicians who offered expert based information on aspects of treatment for patients. In addition, content on the website was updated, and our informative newsletter the Forum was circulated three times within the year. Last but not least, the one-on-one conversations that we had with so many of you were inspiring and informative. We continue to see a growing need for clear, understandable information about cutaneous lymphoma that puts this disease into a framework to help support those affected by this challenging diagnosis. Just when we think we are doing enough, another opportunity comes around to step up to offer a new way to connect, communicate and serve this rare group of individuals.

With that in mind, after 4 years of our successful CLARIONS research grant award program, we have undertaken a new initiative to determine how the Cutaneous Lymphoma Foundation, and all of you, can help support research in all of its various shapes and sizes specific to cutaneous lymphoma. Having created our new Research Advisory Council lead by Pierluigi Porcu, MD and Christina Eischens, PhD, we are working hard behind the scenes to gain an understanding of the gaps in research and where the CLF can play the most impactful role. It will take us time to do this initial analysis through discussions with researchers, scientists and clinicians in the field and we are committed to driving forward into the future to support the best and brightest in their endeavors to understand this disease, create new treatments and perhaps one day a cure or way of preventing it all together.

When that day comes, it will be time for us to close our doors as we will not be needed anymore. Until then, we continue to work as hard as we can to serve the best interests of each and every person impacted by cutaneous lymphoma in all its variations. The pages that follow will give you insight into the accomplishments for this year.

I'm always inspired by this quote from the brilliant anthropologist Margaret Mead "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

Together we can change the world for everyone living with cutaneous lymphoma.



2001 - As a member organization of the Coalition of Patient Advocates for Skin Disease Research, the Foundation represented the cutaneous lymphoma community on an advocacy day in Washington.

2002 - The Foundation published its website dedicated to cutaneous lymphoma on the Internet.

2002 - The Foundation established its first Board of Directors and Medical Advisory Board.



BOARD OF DIRECTORS & STAFF

OUR MISSION

Support every person affected by cutaneous lymphoma by promoting awareness and education, advancing patient care and fostering research for the best possible outcomes.

OUR VISION

To be recognized as the worldwide leader in providing cutaneous lymphoma resources and support focused on improving the quality of people's lives, and supporting research that fosters innovation leading to the discovery of a cure.

OFFICERS

President: Joe Eischens, Esquire

Vice President: Marianne Tawa, RN, MSN, ANP
Dana-Farber Cancer Institute

Treasurer: Jeff Ward

Secretary: Laurel Carlson

DIRECTORS

Director: Steven Horwitz, MD

Memorial Sloan Kettering Cancer Center

Director: Youn Kim, MD

Stanford Cancer Center

Director: Lauren Pinter-Brown, MD

Chao Family Comprehensive Cancer Center

Director: Michael W. Young

Chief Executive Officer: Susan Thornton

STAFF

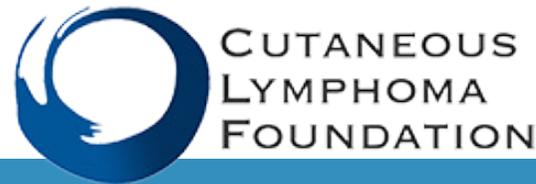
Chief Operating and Financial Officer: Holly Priebe

Program Manager: Hilary Romkey

Information Technology Manager: Deb Van Zegeren

Administrative Assistant: Sue Arnot

20 Years of Service and Support...



2003 - The Foundation hosted its inaugural Cutaneous Lymphoma Symposium as part of the IID meeting; and offered a Young Investigator Award to a presenting researcher for travel to the SID annual meeting.

2005 - To more accurately reflect the range of illnesses and true nature of the disease, the *Mycosis Fungoides Foundation* changed its name to the **Cutaneous Lymphoma Foundation**.



2005 - The Cutaneous Lymphoma Foundation partnered with the late Dr. Marie-France Demierre to survey the CTCL community about their quality of life - the first of its kind study.

OUR PROGRAMS & SERVICES

Our patient education programs are the cornerstone of our services. These live programs are held across the United States, Canada, and more recently have expanded into other countries. 2018 included eight successful live events including our annual *2-Day Patient Educational Conference* in Washington, DC with our highest patient turnout in the last five years as well as an international *Answers from the Experts... Live* in Switzerland.

These live programs have continued to connect patients all over the world with clinicians as well as bringing people affected by cutaneous lymphoma together.

In 2018, our online educational content continued to be reviewed and updated on an ongoing basis to remain up-to-date and relevant. This year over **80,000** visits have been made to the website and views of the videos on the Online Learning Center have exceeded **35,000**. As the only source of clinically-vetted, patient- focused educational and informational material specific to cutaneous lymphoma, the Foundation continues to be the online resource recommended around the world.

The Forum newsletter continues to cater to the feedback of our community. 2018 brought a fresh new layout to the Forum while continuing to provide up-to-date clinical and quality-of-life content to patients and their families all over the United States. With the inception of the Cutaneous Lymphoma Foundation's Medical Advisory Committee, our clinical content is more intriguing than ever. We have continued to expand our Skin Care Corner and information for caregivers and families as well.

Facebook Live interviews have continued to allow patients valuable access to clinicians in a virtual setting all over the world. These monthly interviews have allowed us to expand our reach to the cutaneous lymphoma community and bring patients together with physicians not in their area. Esteemed clinicians continue to provide important lectures on a wide variety of topics and have allowed us to assist patients in networking with each other as well. Our News & Insights Facebook pages (Sezary Syndrome and MF) also assist in connecting patients with others and getting the most updated information on their particular disease.



2005 - Patient educational events were introduced offering expert clinical information and networking opportunities.



2009 - The Summit - a three day continuing education (CE) opportunity for both physicians and nurses, with a simultaneous patient education event bringing all members of the cutaneous lymphoma community together.

COMMENTS FROM EVENT ATTENDEES:

"This was my first conference since a Nov. 2015 diagnosis and it was GREAT,"

"I am glad the Foundation is here, good information, good support,"

"This was a Class A event that allowed me to interact with patients that have the same disease that I have. Bottom line is I no longer feel alone."

RESEARCH

Research continues to be high on the list of priorities for the Foundation. The Research Advisory Council and Board of Directors' have approved an interim research award to be launched in the summer of 2019.

Along with the new research awards program, we also expanded this year's Young Investigator Award program offering three travel grants. We proudly awarded researchers in cutaneous lymphoma at the Society for Investigative Dermatology (SID), American Society for Homology (ASH) in addition to the European Organization for Research and Treatment of Cancer (EORTC) annual meetings. To learn more about this year's recipients visit the website at <https://www.clfoundation.org/young-investigator-award>.

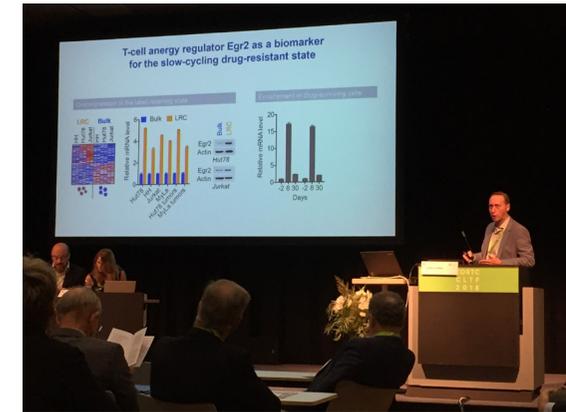
The organization is excited about the research being done in cutaneous lymphoma and thrilled to be able to contribute.



2018 IID Young Investigator Award Recipient:
Carina Dehner, MD
Washington University School of Medicine



2018 ASH Young Investigator Award Recipient:
Pamela Allen, MD, MSc
Winship Cancer Institute of Emory University



2018 EORTC Young Investigator Award Recipient:
Stefan M. Schieke, MD
University of Wisconsin School of Medicine and Public Health



2013 - The first annual 2-Day Patient Conferences was held, providing clinical, health and wellness information.



2012 - The CLARIONS (Curing Cutaneous Lymphoma by Advancing Research, Innovation and Offering New Solutions) research award was launched.

2012 - A Patient's Guide to Understanding Cutaneous Lymphoma was published. A comprehensive educational publication, the guide provides patients and caregivers with in-depth cutaneous lymphoma information.



20 Years of Service and Support...

ALLIANCES

The Cutaneous Lymphoma Foundation partners with the following organizations to enhance its work of making sure that each person with cutaneous lymphoma gets the best care possible:

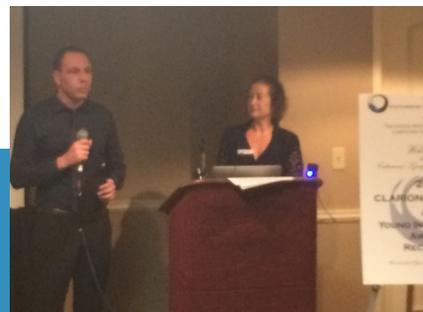
American Academy of Dermatology
American Society of Hematology
Canadian Skin Patient Alliance
Cancer Support Community
CancerCare
Coalition of Skin Diseases
Dermatology Nurses Association
Genetic Alliance
International Alliance of Dermatology Patient Organizations
International Society for Cutaneous Lymphomas
Leukemia & Lymphoma Society

Lymphoma Coalition*
Lymphoma Foundation Canada
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
National Organization for Rare Disorders
Partnership to Improve Patient Care
Patient Access Network Foundation
Regulatory Education and Action for Patients
Society for Investigative Dermatology
T-Cell Leukemia Lymphoma Foundation
Triage Center
United States Cutaneous Lymphoma Consortium

**Cutaneous Lymphoma Foundation CEO is a board member.*



2013 - CLF established a formal networking group for patients and caregivers in Washington DC. Four groups have since been started.



2013 - The first CLARIONS research grants were awarded.

2014 - *Understanding Treatment Options in Cutaneous Lymphoma* was published. A companion to the Patient's Guide, the treatment guide provided a detailed overview of treatment options

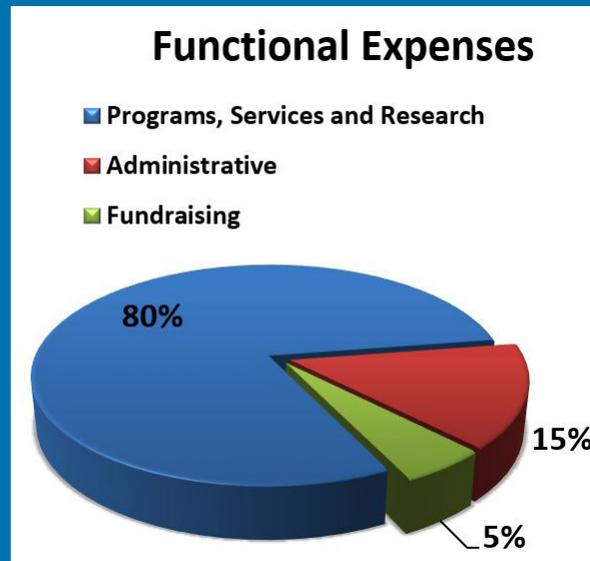


FINANCES

We are excited about what we have accomplished in this past year, and hope you find the same value in the choices we have made. We look forward, with your support, to continuing these efforts and expanding into new areas of support and research for people affected by cutaneous lymphomas.

STATEMENT OF ACTIVITIES • YEAR ENDED JUNE 30, 2018

	Unrestricted	Temporarily Restricted	Total
SUPPORT AND REVENUE:			
Contributions and grants	166,743	723,622	890,365
Merchandise sales, net of cost of good sold of \$21 in 2018 and (\$172) in 2017	21	-	21
Interest income	211	-	211
TOTAL SUPPORT AND REVENUE	<u>166,975</u>	<u>723,622</u>	<u>890,597</u>
NET ASSETS RELEASED FROM TEMPORARY RESTRICTIONS			
	<u>624,709</u>	<u>(624,709)</u>	<u>-</u>
	791,684	98,913	890,597
FUNCTIONAL EXPENSES:			
Program	580,811	-	580,811
Management and general	109,652	-	109,652
Fundraising	37,491	-	37,491
Total functional expenses	<u>727,954</u>	<u>-</u>	<u>727,954</u>
CHANGE IN NET ASSETS	<u>63,730</u>	<u>98,913</u>	<u>162,643</u>
NET ASSETS - Beginning of year	<u>198,590</u>	<u>376,036</u>	<u>574,626</u>
NET ASSETS - End of year	<u><u>\$262,320</u></u>	<u><u>\$474,949</u></u>	<u><u>\$737,269</u></u>



“The CLF does wonderful work. Thank you.”

Comment from Event Survey

STATEMENT OF FINANCIAL POSITION • YEAR ENDING JUNE 30, 2018

	2018	2017
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	759,817	556,671
Promises to give	-	60,000
Inventory	2,205	2,368
Total Current Assets	<u>762,022</u>	<u>619,039</u>
FIXED ASSETS		
Property and equipment	67,375	55,219
Less: Accumulated depreciation	19,742	3,865
Total Fixed Assets	<u>47,633</u>	<u>51,354</u>
OTHER ASSETS		
Prepaid rent	-	1,386
Security deposit	1,386	1,386
Total Other Assets	<u>1,386</u>	<u>2,772</u>
TOTAL ASSETS	<u><u>811,041</u></u>	<u><u>673,165</u></u>
LIABILITIES AND NET ASSETS		
LIABILITIES		
Accounts payable	6,387	15,836
Accrued expenses	67,385	82,703
Total Liabilities	<u>73,772</u>	<u>98,539</u>
NET ASSETS		
Unrestricted	262,320	198,590
Temporarily restricted	474,949	376,036
Total unrestricted net assets	<u>737,269</u>	<u>574,626</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$811,041</u></u>	<u><u>\$673,165</u></u>



THANK YOU TO OUR SUPPORTERS

The Cutaneous Lymphoma Foundation wishes to thank the following corporate partners for their support:



The Cutaneous Lymphoma Foundation is deeply grateful to all the donors who supported our mission through financial contributions during our 2018 fiscal year (July 1, 2017 – June 30, 2018).

Your gifts have enabled us to make sure that 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.

EVERY DONATION HELPS!

Your donations have helped to support over 10,000 people who have been impacted by cutaneous lymphoma, in over 130 countries. Our programs can only be made possible through the generous support of individuals – like you – who care.

We are committed to meeting the increasing demand for our services and invite you to support our work. Your gift directly impacts people around the world touched by cutaneous lymphoma. Your financial contribution allows us to offer help where it's needed most, and continue our mission: to support every person with cutaneous lymphoma by promoting awareness and education, advancing patient care and facilitating research.

20 Years of Service and Support...



2015 - The first annual research report was published. The report included a synopsis of the cutaneous lymphoma research of the CLARIONS and Young Investigator recipients.



2015 - CLF began to livestream our Patient Education Forums allowing people to participate from around the world.

2017 - The original Medical Advisory Board was restructured as the Medical and Research Advisory Councils. Both Councils welcomed new members.

LOOKING AHEAD

Where are we headed from here?

One goal we have is to leverage technology to bring our programs and services to more people where they live. It can be challenging to learn new technology and have the expertise to be able to use it effectively. We ask for your patience as we try new methods and figure out how to use them properly. Let us know what you find valuable and what doesn't work for you.

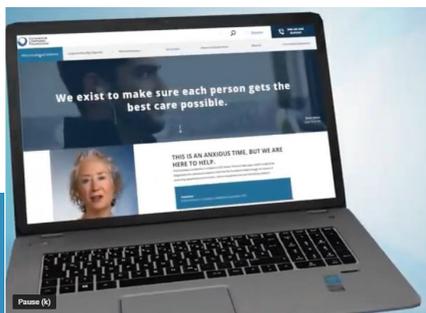
We're often asked by members of our community how to connect with others close to home. Along those lines, we are more committed than ever to expanding our local networking groups across the country. Getting a new group up and running may seem easy, but there are many components behind the scenes that need to be in place to make sure the group can be sustained for the long-term; and we want to support as many of these groups as we can.

While not as much to share, we continue to work on creating a long-term research roadmap with our Research Advisory Council members. Building on the success of our CLARIONS

and Young Investigator research grant programs, we are collaborating with the scientists, researchers and clinicians in the field of cutaneous lymphoma to gather detailed information about the current landscape of research and the gaps that we, as the CLF and patient community, can help to fill. Having a good understanding of where we can play the most impactful part will enable us to create a program along with funding required to support critical initiatives that will benefit all of us today and into the future.

While not always visible to you, know that we are working hard behind the scenes on your behalf. Staying engaged in the field of cutaneous lymphoma, whether it's through policy or regulatory initiatives, research, clinical trials, new treatments or using technology to better connect our community, know that every day we drive toward serving you in the best possible way.

It's a bright future ahead. Together we will change the world for the better for everyone impacted by cutaneous lymphoma.



2017 - The CLF's website was updated and redesigned offering a new look and a mobile-friendly format.

2017 - Patient educational event was hosted in the United Kingdom in conjunction with Lymphoma Association and Guys & St. Thomas' NHS Foundation Trust.



2018 - Facebook Live events are introduced providing live interviews, and Q&A opportunities with clinicians.



The Board of Directors, Officers, Staff and Patients sincerely thank you for the donations made during Fiscal Year 2018

20 Years of Service and Support...



CUTANEOUS
LYMPHOMA
FOUNDATION

PO Box 374 · Birmingham, MI 48012
www.clfoundation.org

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

