

ANNUAL REPORT

Fiscal Year 2019



Beginning the Next Chapter of Service and Support



**CUTANEOUS
LYMPHOMA
FOUNDATION**

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.

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FROM THE CHIEF EXECUTIVE OFFICER

“Let us make our future now, and let us make our dreams tomorrow’s reality.”

Malala Yousafzai

The 2018-2019 fiscal year took the Cutaneous Lymphoma Foundation into the third decade of its existence. It is certainly the beginning of a new chapter in the way we plan to achieve our mission and support everyone living with cutaneous lymphoma, no matter where they are in the world.

We celebrated and recognized our 20th year in December 2018, bringing us to the start of our next chapter in 2019. Each year there are new challenges facing our community of patients and their families. Cost of care and treatment around the globe continues to be a critical issue. Learning about the biology of this complex group of diseases under the cutaneous lymphoma umbrella requires focus and attention if we are to find new treatments and new ways of personalizing the treatments for each person.



Susan Thornton

While our focus has always been, and continues to be, providing clinically vetted, relevant and critical information that our community can count on, we know that getting this valuable information to everyone is just as important. It’s not enough to have the information, but we need to implement new and creative ways of bringing this content to those who speak different languages and live in far off places. We began a project this year to collaborate with our fellow lymphoma patient organizations around the world to raise awareness of cutaneous lymphoma and to provide new ways of engaging patients in their local area. We hosted a program in collaboration with a lymphoma patient organization in Switzerland and the cutaneous lymphoma specialists from St. Gallen, Switzerland. It’s exciting to see our cutaneous lymphoma network expand to include knowledge outside of North America. As we all know, this disease doesn’t have borders.

Continuing to leverage technology in new ways and enhance how we incorporate technology into our current programs and services continues. It's critical to making sure this important information is available to everyone.

While high tech is important, we are also committed to continuing the personalized support and programs that our community counts on us to provide. The 2-day Patient Conference in Manhattan Beach, California, was the best so far. We listened to you and changed the program to reflect smaller and more breakout groups, along with more time for networking and connection. We even had a surprise movie premier! It's incredible to see how many people come year after year, seeing friends and making new connections, along with learning about the latest trends in science, research and the disease itself.

This year our newly formed Research Advisory Council met for a full day to begin the creation of a long-term plan for the Cutaneous Lymphoma Foundation to continue to support research. The outcome was the development of a new Catalyst Grant. The goal is to support innovative research in the field of cutaneous lymphoma and build on the success of our CLARIONS Research Grant initiative that completed in 2017. More to come in the future about our plans to engage proactively in the research arena.

Of course, we could not do any of this work without you. From our corporate sponsors who continue to support us to each individual who finds us a valuable investment, it's imperative that you know how important you are. You enable us to continue to provide our services, and continually find new ways to educate, empower and support each individual and family impacted by cutaneous lymphoma.

This quote from Rumi puts it all in a nutshell:

"Be a Lamp or a Lifeboat or a Ladder"

That is how we focus our efforts each year in service to each person in the cutaneous lymphoma community. We are here to be your lamp, lifeboat or ladder in making the journey with cutaneous lymphoma a little bit easier through knowledge, empowerment and personal connection.

Thank you for your support and commitment to people living with cutaneous lymphoma around the globe.

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.

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.

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The Cutaneous Lymphoma Foundation was founded on the idea that all people affected by cutaneous lymphomas should get the best care possible. The numbers indicate that we continue to expand both our programs and services, along with our reach across the world.

Educational and Networking Opportunities:

In the last fiscal year, the Cutaneous Lymphoma Foundation offered four Patient Educational Forums, three Answers from the Experts, one 2-day Patient Conference, six Networking Groups, 11 Facebook Live events, four livestreaming opportunities and more! Survey results indicate people find great value in feeling a connection to others. In-person programs provide both empowerment and education through sharing space with experts and others facing the same disease – something many would otherwise never have the opportunity to experience. Therefore, expanding the educational and networking opportunities to include more online programs, enabling even more people affected by cutaneous lymphoma around the world to educate themselves and connect, is high on our list of priorities.

Forum Newsletter and Research Report:

This year, just over 22,000 paper copies of the Forum newsletters were distributed. This is an increase of 250 new people receiving this publication, which is published three times a year and is filled with patient stories, information on skin care, treatments and other articles addressing what is going on in the world of cutaneous lymphoma. In addition to the Forum, we mailed 7,250 copies of the Research Report, educating people on the research projects being funded by the Cutaneous Lymphoma Foundation on behalf of those affected by cutaneous lymphomas.

Website:

The statistics show that new users are make up the majority of the traffic that visit the website, at 85% of those who sign on. Those who find the Cutaneous Lymphoma Foundation's website, gaining access to valuable resources, such as clinically vetted educational publications and videos, treatment center and clinical trial information, event information and much more, has increased by nearly 45% over the previous year.

Literature Requests:

Nearly 2,250 copies of educational materials were mailed around the world to 250 households and physicians' offices. This doesn't include the thousands more copies that are downloaded electronically every day. Getting educational materials in the hands of those who need it is an important part of empowering people to take control of their disease and continues to be an important part of what we do.

Ensuring all people affected by cutaneous lymphomas get the best care possible is the focus of every program and service provided by the Cutaneous Lymphoma Foundation, both as we carry on with our ongoing programs and services, and as we develop new initiatives.

RESEARCH ADVISORY COUNCIL

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Pierluigi Porcu, MD, *Thomas Jefferson University*
Barbara Pro, MD, *Robert H. Lurie Comprehensive Cancer Center*

In August of 2018, members of the Cutaneous Lymphoma Foundation Research Advisory Council convened for a day-long planning workshop in Philadelphia, Pennsylvania. The group worked together to develop a recommendation for both short-term and long-term objectives for supporting research and advancing care in the area of cutaneous lymphomas. As a result, at the end of June 2019, as we prepared to launch our two-year interim research awards program, the Cutaneous Lymphoma Catalyst Research Grant – four separate \$50,000 research grants the first year and two additional \$50,000 grants in the second year.

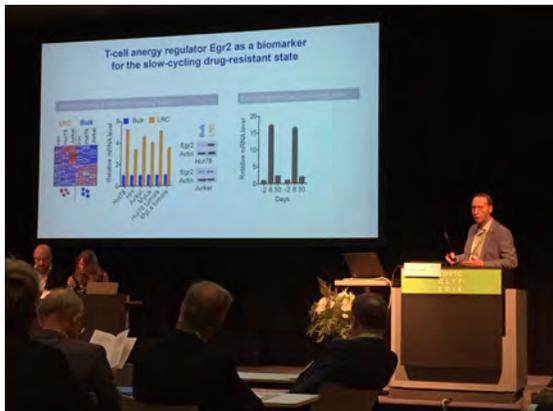


In addition to the research funding, we also continue to support researchers early in their careers who are working in the area of cutaneous lymphoma. Four separate \$1,500 travel awards were offered this year as part of the Young Investigator Award program. These awards allowed for researchers to attend the Society for Investigative Dermatology (SID), American Society of Hematology (ASH) and the European Organisation for Research and Treatment of Cancer (EORTC) medical meetings to present their work to the broader research communities.

Stay tuned as the Research Advisory Council, along with the Board of Directors, plan to announce the finalized Research Roadmap soon. The Cutaneous Lymphoma Foundation is dedicated to supporting research to support you through advancing treatments and care, and to hopefully someday finding a cure.



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

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:

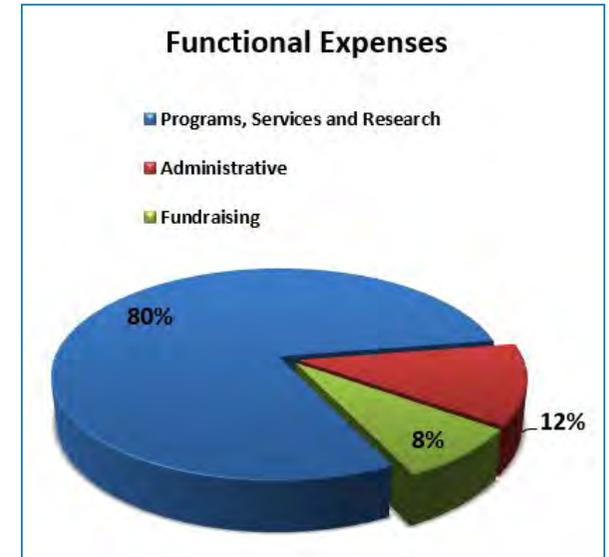
- American Academy of Dermatology
- American Society of Hematology
- Canadian Skin Patient Alliance
- Cancer Support Community
- CancerCare
- Coalition of Skin Diseases
- Dermatology Nurses Association
- Genetic Alliance
- Haystack Project/Rare Cancer Network
- International Alliance of Dermatology Patient Organizations*
 - RareDERM
- International Society for Cutaneous Lymphomas
- Leukemia & Lymphoma Society
- Lymphoma Coalition**
- Lymphoma Canada
- Lymphoma Research Foundation
- National Coalition for Cancer Survivorship
- National Organization for Rare Disorders
 - Rare Cancer Coalition
- 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 is a founding board member.

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STATEMENT OF ACTIVITIES • YEAR ENDED JUNE 30, 2019

	Unrestricted	Temporarily Restricted	Total
SUPPORT AND REVENUE:			
Contributions and grants	207,915	860,300	1,068,215
Merchandise sales, net of cost of good sold of \$0 in 2019 and (\$21) in 2018	-	-	-
Interest income	3,758	-	3,758
TOTAL SUPPORT AND REVENUE	211,673	860,300	1,071,973
NET ASSETS RELEASED FROM TEMPORARY RESTRICTIONS	738,502	(738,502)	-
FUNCTIONAL EXPENSES:			
Program	670,017	-	670,017
Management and general	103,537	-	103,537
Fundraising	67,223	-	67,223
Total functional expenses	840,777	-	840,777
CHANGE IN NET ASSETS	109,398	121,798	231,196
NET ASSETS - Beginning of year	262,320	474,949	737,269
NET ASSETS - End of year	\$371,718	\$596,747	\$968,465



“Many thanks. Finding you was immensely helpful. I no longer feel alone.”

Comment from Event Survey

STATEMENT OF FINANCIAL POSITION • YEAR ENDING JUNE 30, 2019

	2019	2018
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	915,500	759,817
Promises to give	110,274	-
Inventory	386	2,205
Total Current Assets	<u>1,026,160</u>	<u>762,022</u>
FIXED ASSETS		
Property and equipment	67,375	67,375
Less: Accumulated depreciation	40,912	19,742
Total Fixed Assets	<u>26,463</u>	<u>47,633</u>
OTHER ASSETS		
Prepaid rent	2,946	-
Security deposit	1,386	1,386
Total Other Assets	<u>4,332</u>	<u>1,386</u>
TOTAL ASSETS	<u><u>1,056,955</u></u>	<u><u>811,041</u></u>
LIABILITIES AND NET ASSETS		
LIABILITIES		
Accounts payable	8,265	6,387
Accrued expenses	80,225	67,385
Total Liabilities	<u>88,490</u>	<u>73,772</u>
NET ASSETS		
Unrestricted	371,718	262,320
Temporarily restricted	596,747	474,949
Total unrestricted net assets	<u>968,465</u>	<u>737,269</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$1,056,955</u></u>	<u><u>\$811,041</u></u>

“...I trust the Cutaneous Lymphoma Foundation to supply me with good information...”

Comment from Event Survey

YOUR GIFT HAS MADE A DIFFERENCE. THANK YOU.

The generosity of our donor community enables us to bring our mission to life on a global level. As we finalize small details from this year to share with you publicly, we'd like to take this moment to express our deep gratitude to each individual who contributed to the success of the Foundation this year. We simply could not have done it without you!

A special note of thanks goes to:

First time donors – we are truly grateful for your decision to support our mission and for joining our community.

Recurring donors – your ongoing generosity is what gives our patient community the resources and support it needs. It also helps to impact future patients.

Major donors – it is so encouraging when we receive gifts from you because it allows us to assist one more patient, one more caregiver, and one more person who may be affected by cutaneous lymphoma, both now and in the future.

Friends & family who made a contribution on behalf of someone living with cutaneous lymphoma – as a patient advocacy organization, we are able to impact many lives throughout the year because of supporters like you.

Dollars raised this year to support the Cutaneous Lymphoma Foundation were more than at any point in our 20+ year history, totaling in excess of \$185,000, and the best is still to come. Your donations have helped to support over 10,000 people who have been impacted by cutaneous lymphoma. Our programs can only be made possible through the generous support of individuals – like you – who care.

Thank you!

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



As we look into the next year and beyond, where are we headed?

Of course, continuing our educational programs and services is at the top of the list. Finding new ways of bringing this vital information and knowledge into the hands and homes of each person who needs it through leveraging technology is imperative.

Building on our pilot project to bring this knowledge out into the world through building a network of individuals and organizations globally to support people in their own country and in their own language is critical. Cutaneous lymphoma doesn't know borders and we can't allow language or distance to keep us from providing access to information to those who need it, no matter where they live or the language they speak.

Data and research - these two go hand-in-hand. Gathering data about the patient and caregiver experience can help inform research and help to facilitate the need for new treatments and ways of managing this disease. Supporting research and researchers who are working diligently to learn more about the biology of this complex group of diseases is critical to finding new ways

to treat and enhance the quality of life for every person impacted.

And then there is advocating on behalf of each individual to have access to treatments and specialists, and the ability to afford them. While we cannot do this on our own, collaborating and being in partnership with larger consortiums and policy initiatives globally, raises the voice of cutaneous lymphoma patients and the impact these issues have. It's why we are looking at new ways to learning more about the collective experience of patients and their families who are living with cutaneous lymphoma. Having data and personal stories that we can share at a regional, national, and international level can make a difference.

There remains much work to do to bring more tools, resources and information to patients, families and healthcare providers. It's a multifaceted approach to using everything we have at our disposal to fulfill our vision and our mission to make sure everyone impacted by cutaneous lymphoma gets the best care possible.

Join us for the next chapter in our journey. Together we will make a difference for everyone.





The Board of Directors, Officers, Staff and Patients sincerely thank you for the donations made during Fiscal Year 2019.



CUTANEOUS
LYMPHOMA
FOUNDATION

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www.clfoundation.org

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