



CUTANEOUS LYMPHOMA FOUNDATION

# Research Roadmap

February 2021

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Cutaneous  
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## [ The History of Cutaneous Lymphoma Research ]

A road map must have a starting point in order to provide directions to a destination. This is true of actual physical travel as well as in cutaneous lymphoma research. In the case of cutaneous lymphoma, the starting point towards better diagnostics, treatment and, one day, a cure began in the 1800's with Baron Jean-Louis Alibert (1768-1837).

Baron Jean-Louis Alibert's area of medical interest was chronic diseases, including skin conditions. He helped establish dermatology as a medical specialty and began the first dermatological school at the Saint-Louis Hospital in Paris, France. While Alibert only saw one case of mycosis fungoides in his lifetime, he helped distinguish it as a distinct disease during a time when there was much confusion about skin diseases. He was the first to use the term "mycosis fungoides" in 1806 to describe the mushroom-like appearance of tumors on a patient's skin.<sup>1</sup>

It was in 1870 when Ernest Bazin (1807-1878), a student of Dr. Alibert, described the progression of mycosis

fungoides from patches to plaques to tumors – descriptions that are still used today.<sup>1</sup>

Then in 1938, the French dermatologist Albert Sézary and the cardiologist Yves Bouvrain discovered a condition that included reddening of the skin (erythroderma), enlarged peripheral lymph nodes and irregular blood cells that circulated in the bloodstream. The condition they described was an aggressive form of cutaneous lymphoma formally named "Sézary syndrome" in 1949.<sup>1</sup>

It was not until the 1970s that physicians and scientists began to understand the cancerous origins and features of mycosis fungoides. It was in 1975 that the term cutaneous T-cell lymphoma (CTCL) was introduced to encompass the diseases of mycosis fungoides and Sézary syndrome. This resulted from the understanding of the similarities between these two forms of cutaneous T-cell lymphoma - the cell of origin of both was determined to be skin homing T-cells.<sup>2,8</sup>

*continued on page 2*



Susan Thornton with ISCL founding member, Dr Eric Vonderheid and Judy Jones



The Foundation's Medical Advisory Board members present at the Cutaneous Lymphoma Summit



Dr. Maire-France Demierre, the first researcher to study quality of life, with Michael Young and Judy Jones

The growth of cutaneous lymphoma knowledge suffered in large part due to the low incidence of the disease, providing researchers access to small pools of patients and data.<sup>8</sup> The creation of the International Society of Cutaneous Lymphoma in 1992 was a significant milestone in moving cutaneous lymphoma research forward. As described on the organization's website, the initial idea occurred at the World Congress of Dermatology held in June 1992. It was at this conference that specialists in cutaneous lymphoma decided to develop a collaborative group to "facilitate the sharing of information and coordinate activities in this field worldwide."<sup>3</sup> The group was named the "International Cutaneous Lymphoma Interest Group" and was founded by the following individuals:

- |                     |                           |
|---------------------|---------------------------|
| Günter Burg         | Neil Smith                |
| Sergio Chimenti     | Pierre Souteyrand         |
| Benvenuto Giannotti | Wolfram Sterry            |
| Peter Heald         | Kristian Thomsen          |
| Helmut Kerl         | Ramón Torné               |
| Robert Knobler      | Ralph Trüeb               |
| Jose Diaz-Perez     | Willem VanVloten          |
| Katty Peris         | Eric Vonderheid           |
| Nicola Pimpinelli   | *Three members not listed |
| Donald Rosenthal    |                           |

The group held their first formal meeting in December 1992 in conjunction with the 51st Annual Meeting of the American Academy of Dermatology (AAD). The organization was eventually renamed to the "International Society of Cutaneous Lymphomas" (ISCL). In addition to annual meetings of the ISCL at the AAD, major scientific meetings were organized together with or within the program of the World Congress of Dermatology meetings. Some accomplishments of the ISCL-sponsored workshops include the comparison of different methods to quantify skin tumor burden in cutaneous T-cell lymphoma (CTCL), a consensus report on terminology and hematologic criteria for use in patients with erythrodermic CTCL, a scoring system for diagnosis of clinically typical mycosis fungoides, and a consensus report on staging and classification of CTCL.<sup>3</sup>

Another international symposium, Cutaneous Lymphomas: A Challenge for the Pathologist and the Clinician, took place at the University Hospital of Zurich in 2000. Specialists dedicated to cutaneous lymphoma from throughout the world presented on topics related to diagnosis, variants, classification of tumors and treatments as part of this scientific program.

In 2009 the United States Cutaneous Lymphoma Consortium (USCLC) was established. The USCLC is a multidisciplinary professional organization dedicated to improving the quality of life and prognosis of patients with cutaneous lymphomas through discovery and application of new knowledge. The USCLC represents the only organization in America where professionals from various disciplines (dermatology, medical oncology, radiation oncology, and pathology) can exchange ideas and practice tips, discuss and plan scientific collaborations, develop new educational tools, and help shape the research agenda in cutaneous lymphoma.<sup>4</sup>

In October 2009, the Cutaneous Lymphoma Foundation sponsored and hosted the Cutaneous Lymphoma Summit in New York City. The Summit served as a forum for the discussion of bold ideas, explore controversial or poorly developed areas of research, and spark lively discussion among leading investigators from both within and outside the field. It was an inclusive gathering to identify unifying issues important to all stakeholders (patients and families, nurses, social workers, physicians, and scientists from different disciplines). Participating in the Summit were the United States Cutaneous Lymphoma Consortium (USCLC), the International Society of Cutaneous Lymphomas (ISCL), and the Cutaneous Lymphoma Working Group of the European Organization for Research and Treatment (EORTC).<sup>6</sup>

The Summit gave rise to the First World Congress of Cutaneous Lymphomas held in Chicago, Illinois, in September 2010. The purpose of the World Congress was, and is, to provide a premier interdisciplinary

platform for all participants (basic scientists, dermatologists, hematologists, clinical oncologists, dermatopathologists, radiation oncologists, and others) not only to share the updates and the most recent advances in cutaneous lymphoma research, but to also discuss practical challenges in the field of cutaneous lymphomas.<sup>7</sup>

The first Congress was sponsored by the International Society for Cutaneous Lymphomas (ISCL), the United States Cutaneous Lymphoma Consortium (USCLC) and the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. The World Congress has evolved into a tri-annual major medical meeting. The European Organisation for Research and Treatment for Cancer-Cutaneous Lymphoma Task Force (EORTC CLTF) joined the ISCL and USCLC as a co-sponsor of the event in 2013 and each Congress subsequently.

The purpose of this brief history is to visit the milestones in cutaneous lymphoma's research journey from a handful of very early medical professionals to the current worldwide collaboration and sharing of information between interdisciplinary professions - all with the intention of improving the understanding of this rare disease and its treatment and one day, its cure.

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- 4 United States Cutaneous Lymphoma Consortium (website). **Mission Statement.** ([https://www.usclc.org/aboutus\\_mission.php](https://www.usclc.org/aboutus_mission.php))
- 5 Lessin S, Porcu P 2009, **The State of Cutaneous Lymphomas: A Call to Action.** *Proceedings From the Cutaneous Lymphoma Summit 2009*, pp S55-S57.
- 6 Jones J, 2009, **Foreword: Cutaneous Lymphoma Summit 2009.** *Proceedings From the Cutaneous Lymphoma Summit 2009*, pp S49.
- 7 International Society for Cutaneous Lymphoma (website). **World Congress of Cutaneous Lymphomas.** (<https://cutaneouslymphoma.org/meetings/wccl/>)
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# Cutaneous Lymphoma Foundation

## Our Research History

The Cutaneous Lymphoma Foundation was formed in 1998. Its mission, to ensure the best care possible for all persons diagnosed with cutaneous lymphoma, was born from the experience of a patient, Judy Jones, navigating the health care system in search of reliable information, expert care, and hope. The fragmentation of resources associated with cutaneous lymphomas across multiple clinical disciplines, inspired the need to create a more collaborative multidisciplinary community involved in research, clinical care, and advocacy.<sup>1</sup>

A co-founder of the Cutaneous Lymphoma Foundation and a cutaneous lymphoma specialist and researcher, Dr. Stuart Lessin best described the significance of the Foundation's creation in an article in the Foundation's newsletter, the *MFF Forum*, in 2001. Dr. Lessin said "With recent cloning of the human genome and an unprecedented increase in the annual budget of the National Institutes of Health (NIH), the capacity of the biomedical investigators to advance our knowledge of CTCL has never been greater. Along with this unprecedented convergence of resources, there has been the organization of CTCL patients in support groups. These support groups have filled a critical need of uniting CTCL patients and providing them with basic, but hard to find, information about their disease. Now, from these support groups, emerges a patient advocacy group, the Mycosis Fungoides Foundation (renamed the "Cutaneous Lymphoma Foundation" in 2005)."<sup>2</sup>

Dr. Lessin further added "The role of patient advocacy groups cannot be overstated. The power of patients and their families can transform nations' attitudes and commitment to human diseases. The Mycosis Fungoides Foundation is in an unprecedented position to play a leadership role in organizing and expanding government, academic, health services, and industry resources for CTCL. For too long, CTCL patients have not had

an effective voice in the halls of Congress and the NIH. For years, academic medical centers struggled to sustain inter-institutional collaborations regarding CTCL studies. Pharmaceutical companies hesitated to test products in CTCL due to real and imagined obstacles in identifying significant numbers of CTCL patients. The Mycosis Fungoides Foundation is in the process of reversing these trends and providing a national and international identity to the thousands of CTCL patients through initiatives in education, communication, and research."<sup>2</sup>

The Foundation's early involvement in research began in 2003 when it established the Young Investigators Travel Awards. The travel awards are given to cutaneous lymphoma physicians and scientists early in their career development to present their cutaneous lymphoma research at various annual medical meetings including the Society for Investigative Dermatology (SID), the American Society of Hematology (ASH), and more recently, the European Organization for Research and Treatment of Cancer -Cutaneous Lymphoma Task Force (EORTC-CLTF) and the World Congress of Cutaneous Lymphomas (WCCL).

In 2005, the Foundation provided a research grant to fund Dr. Maire-France Demierre's quality of life survey. This was one of the first studies to report quality of life issues in cutaneous lymphomas and was the first to recruit research subjects from the Foundation's membership.

The Foundation provided Dr. Martin Weinstock a research grant for his epidemiology study in 2007. The study was the major source for reporting the incidence of cutaneous lymphoma in the United States.

As previously highlighted, in 2009 the Foundation sponsored and hosted the Cutaneous Lymphoma Summit

in New York City. The idea for the Summit was generated three years earlier by the Foundation’s leadership whose vision was that the cutaneous lymphoma community would benefit from an inclusive gathering to identify unifying issues important to all stakeholders (patients and families, nurses, social workers, physicians, and scientists from different disciplines).

The outcomes of the Summit were published as “*Proceedings From the Cutaneous Lymphoma Summit 2009*” which included calls to action in the areas of research, clinical care, and patient, physician, and nursing education. The Summit is also notable for giving rise to the establishment of the World Congress of Cutaneous Lymphomas - a premier interdisciplinary (basic scientists, dermatologists, hematologists, clinical oncologists, dermatopathologists, radiation oncologists, and others) scientific conference dedicated to cutaneous lymphoma.

In 2012, Dr. Emilia Hodak received a research grant from the Foundation for her research in co-morbidities. Hers was one of the first studies to identify non-cancer illnesses associated with cutaneous lymphomas.

2012 also marked a significant turning point in the Foundation’s involvement in research with the formation of a Research Awards Program and the CLARIONS research grant award. CLARIONS (Curing Cutaneous Lymphoma by Advancing Research, Innovation and Offering New Solutions) was the first dedicated research awards program exclusively for cutaneous lymphoma. The CLARIONS Research Award Program concluded in 2018 and funded eight researchers, with a total of fourteen awards, equaling \$350,000 in direct research support.

As the CLARIONS Research Award Program came to a close, the Foundation’s Board of Directors were committed to continuing to fund cutaneous lymphoma specific research. As part of that commitment, and in an effort to ensure the Foundation’s funding makes the greatest impact, the Research Advisory Council was formed to provide scientific guidance for building a robust, sustainable research platform. The Research Advisory Council includes patient representatives as well as researchers and clinicians across all disciplines. Their charter is to explore and construct recommendations to the Board of Directors on where the Foundation should focus its research efforts.

Based on the Council’s recommendations, in 2019, the Foundation launched its Cutaneous Lymphoma Catalyst Research Grant. The Catalyst grant provides researchers with the funding needed to continue and/or complete work being done in cutaneous lymphoma. This short-term research program awards two (or more depending on funding) \$50,000 grants per year.

As the Catalyst Research Grant program draws to a close, the Foundation continues to focus on building a long-term, sustainable research program establishing the Foundation as the home for cutaneous lymphoma research. The next step in achieving this vision is the 2023 Request for Applications (RFA) program.

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1 Lessin S, Porcu P 2009, **The State of Cutaneous Lymphomas: A Call to Action.** *Proceedings From the Cutaneous Lymphoma Summit 2009*, pp S55-S57.  
2 Lessin S 2001, **After Two Centuries, Mycosis Fungoides Foundation Brings One Voice to CTCL.** *MFF Forum*, Vol 1, Ed 1, 2001, p3.



**Dr. Stuart Lessin with Young Investigator Dr. Christiane Querfeld and Judy Jones**



**2018 Research Advisory Council (two members not pictured)**

# Cutaneous Lymphoma Foundation

## Our Research Impact

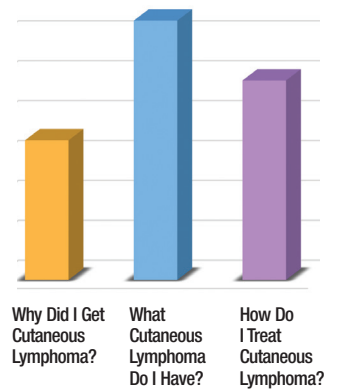
For over 20 years, the Cutaneous Lymphoma Foundation’s primary mission has been to provide education and support for patients with cutaneous lymphoma. Since 2005, that mission has slowly expanded to include “facilitating research” leading to a combined total of 51 awards and grants to support cutaneous lymphoma researchers around the world.

With over \$650,000 invested in cutaneous lymphoma researchers – can you imagine the impact this has made? For such a rare disease, it is significant that the vast majority of the Young Investigators and CLARIONS award recipients remain working in this field. The Foundation’s support gave added visibility and validation to their work when applying for additional funding. This research not only advances care, treatment options and leads us closer to a cure, but each publication from Cutaneous Lymphoma Foundation-funded research raises awareness throughout the larger clinical community.

### Examples of Research “Firsts” Made Through CL Foundation Funding

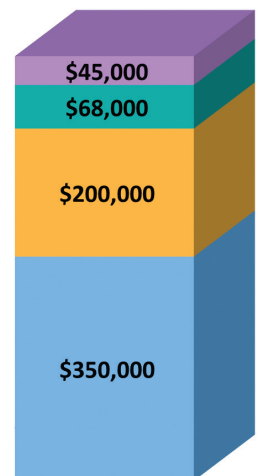
- Quality of life issues in cutaneous lymphoma – Marie Frances Demierre, M.D. Boston University
- Non-cancer illnesses associated with cutaneous lymphoma – Emilia Hodak, M.D. University of Tel Aviv
- Common pathways between thyroid hormone signaling and cutaneous lymphomas – Leandro Cerchietti, M.D. Weill Cornell Medical College
- Personalize medicine for CTCLs by early molecular identification of patients at high risk for progression – John O’Malley, M.D. Ph.D. Harvard University
- Low dose radiation therapy can eliminate cancerous cells from the skin and improve survival in high-risk early stage CTCL – Rachel Clark, M.D. Ph.D. Harvard University
- Skin bacterial toxins stimulate CTCL signaling pathways in a novel mouse model – Sergei Koralov, Ph.D. New York University
- Novel immunologic receptor involved in CTCL signaling that serves as a biomarker and potential therapeutic target – Patrizia Fushiotti, Ph.D. U. Pittsburgh

### Focused on Patients’ Needs Young Investigator Research



### Awards / Grants Provided

- Young Investigator Awards
- Funded Research (other)
- Catalyst Research Grants
- CLARIONS Research Grants



“The CLARIONS award provided a significant boost for my research at a time when I was becoming established in the CTCL field.”

**Patrizia Fushiotti, PhD**



“People pay attention to you when you get this funding. In my experience the CLF chooses the right people for their grants.”

**Larisa Geskin, MD**



# The Cutaneous Lymphoma Foundation Catalyst Research Grant

With the completion of the successful CLARIONS grant program in 2017, the Foundation announced in 2019 its newest research award program, the Cutaneous Lymphoma Catalyst Research Grant.

This award addresses a near term need to accelerate or extend on-going cutaneous lymphoma research that was approved by another funding source. Applications were accepted in 2019 and in 2021 while developing a broader research agenda starting in 2022.

In 2019, four outstanding Catalyst projects were funded. One-time \$50,000 grants were awarded to the following recipients for the 2020 funding period:



Michael Girardi, MD, *Yale University School of Medicine*, “Synergistic Therapy with JAK Inhibition for the Treatment of Advanced CTCL”



Ali Jabbari, MD, PhD, *University of Iowa Carver College of Medicine*, “Extension of Single Cell RNA-Sequencing-Based Analysis of Cutaneous T Cell Lymphomas to Skin-Infiltrating Cells”



Alan Zhou, MD, MSc, *Northwestern University Feinberg School of Medicine*, “Characterization of the skin microbiome in cutaneous T cell lymphoma”



Patrizia Fuschiotti, PhD, *University of Pittsburgh*, “Single-cell transcriptome Analysis of IL-4Ra-Positive Cells in Mycosis Fungoides Skin Tumors”





## Cutaneous Lymphoma Foundation Expanding Our Research Agenda

**THE VISION:** To be *the* home for funding cutaneous lymphoma research.

**2023 REQUEST FOR APPLICATIONS (RFA)** Expanded grant program designed to establish a sustainable source of funding for cutaneous lymphoma research with the ultimate goal of funding ten \$100,000 projects annually.

**RESEARCH AREAS OF INTEREST** Focusing on answering three critical questions posed by patients and to fund the best research projects, our team of top scientists and physicians identified *3 pillars of research*, filling critical gaps in knowledge.

### ***Why Did I Get Cutaneous Lymphoma?***

- Lymphoma cell biology
- Skin immunology
- Lymphocyte-skin interactions
- Genetic/cellular alterations
- Tumor microenvironment

### ***What Cutaneous Lymphoma Do I Have?***

- Diagnosis & staging
- Diagnostic/prognostic biomarkers
- Risk stratification models
- Disease burden & response measures

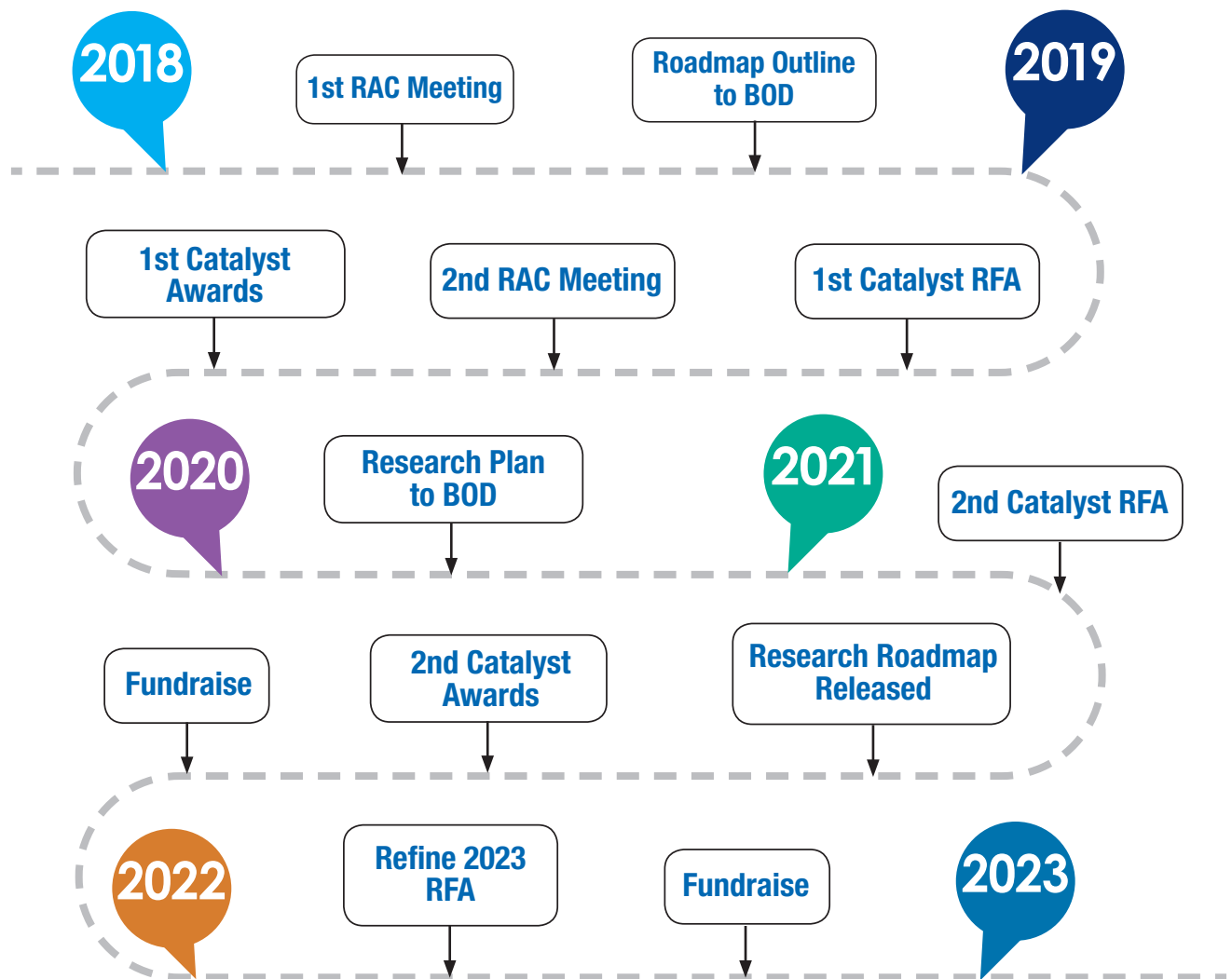
### ***How Do I Treat My Cutaneous Lymphoma?***

- Immunotherapies/targeted drugs
- Personalized therapies
- Improve use of existing therapies
- Quality of life/quality of care
- Biology of itch
- Therapy resistance/relapse
- Population science

**Join our grassroots effort to raise \$1M each year for critical research funding.**

# Our Research Roadmap

*“Building a Home for Cutaneous Lymphoma Research to Improve People’s Lives.”*



**Announcing  
New Research Awards Program**



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