



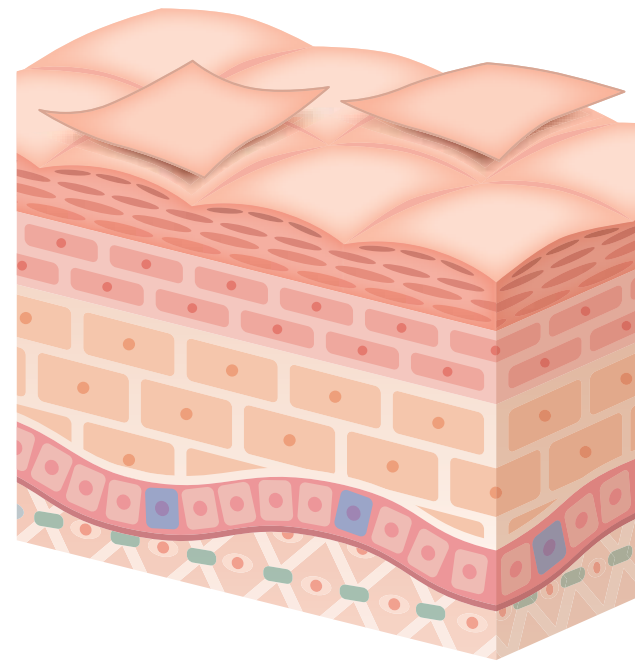
SÉZARY SYNDROME PART ONE: OVERVIEW & DIAGNOSIS

Sézary syndrome is the leukemia version of cutaneous T-cell lymphoma. The main difference between Sézary syndrome and mycosis fungoides are the cells of origin. In patients with Sézary syndrome, the cells of origin are called central memory T-cells, which means that they circulate centrally or within your bloodstream. In mycosis fungoides, the cells of origin are called skin resident effector memory T-cells, which means that they're largely locked in the skin.

Though the cause of Sézary syndrome is still unknown, there have been some associations that have been observed with a small list of medications. These are associations or clusterings, they are not proof of causation. Sézary syndrome does not appear to have a genetic link and is not linked to any unique mutation. It is thought to be an epigenetic phenomenon which means that a complex combination of genetic makeup and lifetime environmental exposures result in disease.

With Sézary syndrome, most of the malignant cells are in the bloodstream; as such, erythroderma is a known hallmark of the disease, meaning diffuse redness with some scaling or peeling of the skin over most of the body. Many patients will also experience hair loss affecting the hair on the scalp, face, or body. Another thing that we see in Sézary syndrome is something called hyperkeratosis, which means that the hands and feet on the palms and soles become very thick and brittle and patients may develop cracks or fissures. These skin changes are unfortunately associated with intense itching or stinging which is severe for many patients and creates the largest challenge in symptom management in Sézary syndrome. Swollen lymph nodes may also occur and can most commonly be felt in the neck, underarms, and groin. The diffuse and intense skin inflammation pulls blood to the skin and robs the body of heat resulting in patients feeling cold or experiencing shivering or chills.

When diagnosing Sézary syndrome, skin biopsy is not as useful as it is with cutaneous T-cell lymphoma mycosis fungoides, because again, the majority of the malignant cells are in the blood rather than the skin. While a skin biopsy is traditionally done and it can give us some useful information, the bulk of our diagnostic information is going to come from an assessment of the blood. This is performed using a flow cytometry machine which



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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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FORUM

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Disclaimer

The Cutaneous Lymphoma Foundation does not endorse any drugs, treatments or products reported in this newsletter. Information is provided for informational purposes only. Because the symptoms and severity of cutaneous lymphoma vary among individuals, the Cutaneous Lymphoma Foundation recommends that all drugs and treatments be discussed with the reader's physician(s) for proper evaluation, treatment and medical care.

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BOARD OF DIRECTORS NEWS

The Cutaneous Lymphoma Foundation would like to thank Dr. Lauren Pinter-Brown for her many years of dedicated service as she steps down from our Board of Directors. As a nationally recognized lymphoma expert, Dr. Pinter-Brown has provided invaluable support to the Foundation from its early beginnings to the present. She has served on our Scientific Review Board, Medical Advisory Board, as a Board member, and as a frequent contributor to our programs and services. We are deeply grateful for all of her years of service.



We wish Dr. Pinter-Brown the very best as she continues to dedicate herself to her patients at UCI Health Chao Family Comprehensive Cancer Center.

FROM THE BOARD PRESIDENT

Laurel Carlson

Does anyone else feel this summer was incredibly short?

After a long winter inside and then a hopeful spring as some aspects of our lives resumed a little bit of normalcy, I think we all were very excited to get out and make up for so much lost time. I hope that you have been enjoying some travel and the ability to be with family and friends again. Unfortunately, as the end of summer draws near, we find our world experiencing an increase in COVID-19 cases once again. That line from Jaws comes to mind, "Just when you thought it was safe to go back..."

And because it was not quite safe enough to go back, our annual Patient Conference was held virtually in June

again this year. If you were not able to join us live for the programs, I hope that you will be sure to watch the recorded sessions. Each part of the program was designed to deliver as much information and support to our patient community as possible. The Q & A with doctors who specialize in treating cutaneous lymphoma patients is always popular and an important opportunity for you to gain more knowledge about your disease.

Through the years, we have had the good fortune to have several dermatologists and oncologists share their experiences and answer your personal ques-

From the President...continued on page 5



"...Our annual patient conference...was designed to deliver as much information and support to our community as possible"

Laurel Carlson

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton



"It's our honor and privilege to serve and support you as you travel on your path."

Susan Thornton

Exhale: It's Summer!

Summer this year feels precious and expansive to me. It has undoubtedly been a long haul from this time last year. As you read this, I hope you are sipping a cool lemonade in the shade of a big tree with your feet up.

First, a deep bow of gratitude to Dr. Lauren Pinter-Brown. Dr. Pinter-Brown has been a devoted volunteer for the Foundation for many years. As she rolls off her official Board service to continue dedicating herself to her patients at UCI Health Chao Comprehensive Cancer Center, I would like to add my personal thanks for all she has contributed. She has been instrumental in making sure the Foundation is clinically credible and providing valuable information for our cutaneous lymphoma

community. If you haven't watched one of her many educational presentations, I encourage you to watch a few. Her down-to-earth and practical way of delivering complex medical information is impressive, and her patients are lucky to have her. Thank you, Dr. Pinter-Brown, for all you have done for us.

From the CEO...continued on page 9



WE ARE EXCITED TO ANNOUNCE THIS YEAR'S CATALYST RESEARCH GRANT AWARDEES

Thank you to every applicant for your interest in the Cutaneous Lymphoma Catalyst Research Grant, and for the incredible work you are doing in cutaneous lymphoma research. We received a record number of proposals for this year's 2021/2022 Catalyst Research Grants and we are pleased to announce this year's awardees:

Prof. Pietro Quagliano from the University of Turin for his project entitled: *Mechanistic insights into the CD39/CD73 adenosinergic immunosuppressive axis in patients with Sézary Syndrome: association with disease course and treatment response*

Assia Angelova, PhD, from German Cancer Research Center (DKFZ) for her project entitled: *H-1 parvovirus-induced oncolysis and tumor microenvironment immune stimulation in a novel heterotypic spheroid model of cutaneous T cell lymphoma*

To learn more about either of these projects, please visit our website (<https://bit.ly/3jglEib>) to see a short explanation provided by each of the researchers regarding their work.

Thank you to our Scientific Review Committee for your expertise, time, and dedication to the Foundation and the scientific review process. Without you, we would be unable to provide these important research grant opportunities.

And to you, our donors, without your support and dedication to the mission of the Foundation, there would be no grants to support this much needed research. Thank you for believing in the mission and for being partners in our vision of a life free of cutaneous lymphomas.

THANK YOU to our Scientific Review Committee for their dedication & commitment

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CRISPR THERAPEUTICS RESEARCHING CAR T CELL THERAPY USING HEALTHY DONOR T CELLS

CRISPR Therapeutics is a leading gene editing company focused on developing transformative medicines for serious diseases. Its proprietary CRISPR/Cas9 platform is intended to modify, delete, or correct errors in DNA. The desire to treat and potentially cure serious diseases defines the company, unites its teams, and inspires its work.



CRISPR Therapeutics has a portfolio of investigational programs across a broad range of therapeutic areas, including T-cell lymphoma. The company is investigating allogeneic CAR T therapy, in which a healthy person donates T cells to a person with a life-threatening disease. T cells are a type of

immune system cell that finds and attacks other cells that may be infected by a virus or should not be in the body. To make CAR T cells, the DNA of the T cell is modified such that it can express chimeric antigen receptors, or CARs, on its surface. A CAR is like a key that locks to a specific protein on the surface of another cell, such as a cancer cell. With this receptor, a goal of allogeneic CAR T cells is to find and kill

cancer cells. Allogeneic CAR T therapy is investigational as its safety and efficacy are still being studied and its use has not been approved by health authorities, including the FDA.

Another form of CAR T cells, called autologous CAR T cells, are made using a patient's own T cells. Some autologous CAR T therapies have been approved for the treatment of specific types of cancer by health authorities, while others are still being studied in clinical trials. Autologous CAR T cells require several weeks to prepare a single dose, and allogeneic CAR T cells can be made in advance and potentially can be present at the treatment facility for a patient to receive as soon as they are determined to be eligible for a CAR T cell infusion by their healthcare provider.

To learn more about CRISPR Therapeutics and its allogeneic CAR T cell therapy approach visit crisprtx.com or ClinicalTrials.gov. Speak to your doctor to understand whether a clinical trial might be right for you or if you have any questions. For more information about CRISPR Therapeutics' commitment to patients, read their Patient Advocacy Charter.

From the President...continued from pg 3

tions. One of those doctors, Dr. Lauren Pinter-Brown, not only has served in that capacity, but until recently, she was also a member of our Board of Directors. As an educator, the first time that I heard Dr. Pinter-Brown speak to our patients, I was impressed by her ability to explain the most complex medical concepts in very understandable language. It took me many years to develop the technique of simplifying language without reducing its content, but Dr. Pinter-Brown seems to have a natural gift for it. One only needs to visit her webpage and read the glowing reviews that her patients have written to see that I am not the only one that she has impressed.

I would like to personally thank Dr. Pinter-Brown for her years of dedicated service to the Foundation. Even before she joined the Board of Directors, she worked with our founders to help create the organization that it has become today. We are all grateful for her contributions to the Cutaneous Lymphoma Foundation and for the continued care and support that she gives to her patients. We wish her all the best as she rolls off of our Board to continue to dedicate herself to her patients and her work.

As we leave summer behind and fall quickly approaches, I hope that you will continue to be cautious. We have come so

far in the past year, and though it appears that our COVID-19 journey is not over yet, we hope you all stay well.

Please stay safe and healthy,



Don't miss out, make sure to subscribe to the Cutaneous Lymphoma Foundation's YouTube channel ([CutaneousLymphomaFnd](https://www.youtube.com/CutaneousLymphomaFnd)) and follow us on Facebook and LinkedIn.

MY CUTANEOUS LYMPHOMA EXPERIENCE... THUS FAR

Shared by Joe P.

I'll mention a quick caveat for those who may have missed the Friday evening session at this year's Virtual Patient Conference: my disease trajectory is even more rare than the cancers we're fighting. If my math is correct, a situation similar to the one I'm experiencing arises in roughly half a percent of cutaneous lymphoma cases. In other words, please don't think your disease will follow suit.

Mystery Bumps

A little over five years ago, I noticed odd bumps on my scalp; they looked similar enough to zits that I assumed they were, so I went on with life as usual, expecting the bumps to go away. But they didn't! Instead, they started to spread. Concerned, I made an appointment to see my primary care physician (PCP).

My PCP thought the "rash" was likely shingles. She gave me a round of antivirals. When the spots on my head kept spreading, she referred me to a dermatologist. One of the bumps had grown quite large by this time. Thus, I went to my dermatology appointment with trepidation. When the dermatologist was done with his inspection, he sat down at his computer and announced I had an infection. He was going to give me antibiotics, and I should schedule a follow-up appointment sometime after. Goodbye! Next patient. My response was, "What? How can this be an infection?" The dermatologist, however, didn't appreciate being questioned.

About a month later as I continued taking the antibiotics, the large bump turned red and began oozing blood. Seeing a large, blood-red, oozing bump on my head inspired an email to the doctor letting him know I needed a biopsy done pronto. Surprise, surprise! The tests showed I had a form of T-cell lymphoma. OMG! Even though I was expecting bad news, the diagnosis virtually knocked the wind out of me.

What Do I Have?

I was at work at the time. Somehow, I managed to get an oncology appointment that very same day. Appointment secured, I rocketed from work, leaving my colleagues wondering, to the oncologist's office to find out what the heck I had and what could be done.

The oncologist told me I had a very rare T-cell lymphoma, primary cutaneous anaplastic lymphoma, and people with this unusual form of cancer tend to die with the disease not from the disease. Whew! That was welcome news! I underwent a PET scan which confirmed the lymphoma was only on my

head, so I was sent for radiation treatment.

The radiation oncology practice was great! They zapped the disease on my head into oblivion and left me with a shiny, glowing red pate. They also reviewed my PET scan – everything, not just my head. One of the nurses sat me down and told me when I was done with my treatments, I should go see a urologist.



Joe (left) and Patrick (right)

What?! But it was true. Like many patients whose battles become complicated due to other opportunistic cancers, I found myself diagnosed with prostate cancer within two months of eradicating the CTCL on my head. I won't belabor the experience except to say my surgery was a complete success. I remain blessedly free of that bugger to this day.

An Odd Development

So! Two cancers extinguished, I was ready to get back to normal life. Or was I? Within six weeks of my prostate surgery, I suddenly developed sciatica. I thought it an odd development, but I know things do wear out over time. So I started seeing medical professionals to find a cause and hopefully a solution for the pain. Turns out, though, I was talking to the wrong doctors. You see, the lymphoma had gone systemic! There was a tumor pressing on my sciatic nerve causing me all that trouble.

Since discovering my cutaneous, indolent lymphoma was having a party all throughout my body, I've become acquainted with many of the drugs and procedures used to treat indolent and aggressive lymphomas (primarily T-cell). Some by reputation and others personally. The ones I've had personal experience with have included chemotherapy, immunotherapy, a drug conjugate (immunotherapy and chemotherapy), and a bone marrow transplant.

Sézary Syndrome...continued from pg 1

Get Educated

What I mean by saying I know some drugs/procedures by reputation is that I've made it my business to get educated about the disease. The Cutaneous Lymphoma Foundation has been a lynch pin in that effort through their online resources, their many great programs for patients to hear from experts, and the networking meetings. I've picked up some very important info and insightful wisdom from fellow patients in those meetings.

Why did I push to educate myself? Well, we do have a rare disease. Not all my doctors have been well versed in this kind of cancer. Actually, none of my regular doctors have been. One of my oncologists even told me she didn't think anything would work for me. Admittedly, things weren't looking good at the time. But that was four years ago. Four years! Clearly, something did work.

Expressing Gratitude

Thank goodness I found my way to the experts. In my experience, getting specialty consultation has been key to receiving the kind of care I need. I don't visit the specialists often, but they've been critical in helping my oncologist see her way toward successful treatment strategies.

Before I wrap it up, I absolutely must mention my stalwart partner, Patrick, who has been through all this with me. He's been an amazing caregiver, cheerleader, and understanding ear. Longsuffering, he even spent two months hunkered down with me in a tiny apartment across the street from Johns Hopkins during my transplant. What a super guy! We were social distancing and wearing masks before it was cool (or a requirement).

Unfortunately, my disease is still active. Although I've been through the transplant and have been a candidate for clinical trials, I haven't found a cure or an enduring remission. We have, however, found a treatment which is currently keeping the lymphoma controlled. Basically, I'm on a maintenance Bexarotene regimen. Hey, I'll gladly take it!

quantifies leukemic cells based on type or by having a pathologist identify the unique shape and characteristics of Sézary cells under a microscope and provide a cell count. Blood is also sent for something called TCR, or T-cell receptor gene arrangement analysis, which can identify the presence of an abnormally large group of identical T-cells suggestive of a malignant clone.

When discussing treatment for Sézary syndrome, I think it's important to point out that there is no specific algorithm or unifying guideline in terms of which medications should be used at what sequence point. We have many different medications to choose from, and they're largely equivocal in terms of their efficacy. Most of these drugs will work in about one-third of patients, and so each patient's care plan is really individualized and based on the patient's potential bad outcomes with side effects or other pre-existing health problems. Mycosis fungoides and Sézary syndrome, though technically different diseases, are both malignancies of the CD4+ T lymphocyte, and therefore the medications that we use to treat these diseases often overlap as well.

There are several categories of drugs that are used to treat Sézary syndrome, including systemic and skin-directed therapies. If you have relatively few circulating Sézary cells, then the recommendation is for combination therapies using category A drugs in combination with skin-directed therapies like phototherapy, total skin electron beam, or topical nitrogen mustard. For patients who have many circulating Sézary cells, the recommendation is often combination therapy, or specifically infused medicines like mogamulizumab and romidepsin plus skin-directed therapies. The role of immune-based therapies is also being explored with many active clinical trials.

In summary, Sézary syndrome is a very rare disease. Expert care is critical, especially in the advanced stages. I suggest that you continue to utilize the Cutaneous Lymphoma Foundation resources to ideally locate a multi-disciplinary cutaneous lymphoma clinic near you. Please remember that many therapies are equivocal and that the decision to pursue a specific treatment is complex, nuanced, and individualized. Always seek opportunities to self-educate and ask your provider questions about your disease and your care plan. This is a confusing disease and largely unknown to most people, including doctors. You should feel comfortable presenting all of your questions to your provider.

Jennifer DeSimone, MD, FAAD
Inova Schar Cancer Institute

**This article is the first of a two-part series to be continued in our Fall edition which will focus on treatment options in Sézary syndrome.*

Frequently Asked Questions

If lymphomatoid papulosis (LyP) is for the most part benign and it doesn't go internally, why do I have to keep seeing the doctor?

"Some patients do develop mycosis fungoides; it's a small number, but I don't know who that person is going to be. We don't have guidance or science to tell us who those people are going to be, so that's why I tell people you need to check in at least once a year, every single year. If you get any new rashes, please come to me first so I can see if it's something common which we can all get like poison ivy or eczema, or if it is really mycosis fungoides. Knowing a person's history is important."

Answer provided by:
Farrah Abdulla, MD, FAAD
City of Hope Medical Center

What type of questions should a newly diagnosed patient with B-cell lymphoma ask their physician?

"Ask what does this diagnosis mean? What is the diagnosis? Is this cancerous or non-cancerous? What subtype? Can I get cured? Is treatment available in general? How do I get prepared for living with this? Is this something I will have to deal with throughout my life? These are good questions you need to prepare.

The critical point is that patients don't know exactly what they have when they come to see me. We are at the tertiary referral center and so we are not making the diagnosis, often we are getting them referred with the specific diagnosis. While I see the pathology beforehand, patients come and then I know it could be this or that, so then when I see the patient, they're not exactly sure; so, I think this is a critical point to discuss the diagnosis first.

I think sometimes we all (physicians) assume the patients know things, but we don't know, and I have been a patient too



and I don't know everything. So that's how it is and nowadays it's very important to know what's going on and then you can prepare accordingly."

Answer provided by:
Christiane Querfeld, MD
*Beckman Research Institute
of the City of Hope*

Questions and responses taken from recordings of our 2021 Virtual Patient Conference Breakout Sessions. For the full-length videos, please visit:

<https://youtu.be/dDqomTFOoQ0>
and
https://youtu.be/ugK0QmON_ko

THERE ARE SO MANY WAYS TO SUPPORT THE CUTANEOUS LYMPHOMA FOUNDATION

Many people think of their Last Will and Testament as the only way to support charities, such as the Cutaneous Lymphoma Foundation, upon their death. Gifts to the Foundation in your Will, or revocable trust for that matter, are very effective ways to support the Foundation, but there are several other very efficient ways of doing so. Let's review some of the more common techniques.

Retirement Accounts

Your retirement account, or any portion of it, whether an IRA, 401(k), 403(b), 457 plan, or almost any other type of qualified retirement account, can easily be left to the Foundation. Upon your death, the funds held in your retirement account are distributed to the beneficiaries you have named. You can name individuals or charities, or a combination of the two as beneficiaries, though care has to be taken when combining both individuals and charities in one beneficiary designation. When retirement funds pass to an individual, he or she must pay income tax on the amounts withdrawn, whereas when the funds pass to the Cutaneous Lymphoma Foundation, the Foundation receives 100% of the funds completely free of any income tax.

Life Insurance Beneficiary

The Foundation can be named as a beneficiary of a life insurance policy. It can also be named as a co-beneficiary with individuals, such as family members, or as a contingent beneficiary, to receive the funds if the primary beneficiary dies before the insured person.

Regarding both retirement accounts and life insurance, you retain the right to change the beneficiary designation at any time by filling out what is usually a short simple form.

Account Beneficiary

Lastly, many states provide that beneficiary designations can be set up for bank or brokerage accounts. This is accomplished by setting up a "POD" (payable on death) or "TOD" (transfer on death) account at a bank or brokerage firm.

If you have any questions or would like to discuss this further, please contact Holly Priebe at the Cutaneous Lymphoma Foundation (holly@clfoundation.org) and your personal estate planning attorney.

From the CEO...continued from pg 3

It's been a busy time with several scientific conferences. You will find highlights from those meetings in this issue. At times, the presentations go a bit deep into the research weeds, but it's always exciting to learn from the experts in the field about what they are uncovering. Whether or not you are interested in the research, the good news is that there is a lot of it being done. Every year, new discoveries are being made into the understanding of this group of rare diseases that impact treatments and new approaches for therapies.

Of course, the highlight of the past few months was the annual Patient Conference held in June. While we hoped to host the meeting in person this year, that wasn't a possibility. Nonetheless, it was delightful to "see" everyone, engage with old friends, and meet new friends. We are looking forward to hosting our first virtual International Patient Conference in September, along with a hybrid in-person/online patient program in Marseille, France. Our goals are to bring valuable education and information to our folks outside the US and build a strong network around the world for individuals to learn and support each other. It's exciting and a bit challenging, and we are going for it! Look for more details as the dates get closer.

As the second half of 2021 unfolds, we will offer our educational programs, virtual networking meetings, and research updates through the website and other communication channels. If you have specific questions or need to connect one-on-one, reach out any time. It's our honor and privilege to serve and support you as you travel on your path.

While we will continue to connect virtually for the remainder of this year, I hope we can begin hosting in-person programs again in 2022 – especially looking forward to our annual Patient Conference next June. In the meantime, know you are never alone.

"Good company in a journey makes the way seem shorter."

Izaak Walton

Journey on friends,



INTERNATIONAL SOCIETY FOR CUTANEOUS LYMPHOMAS ANNUAL SCIENTIFIC MEETING HIGHLIGHTS

This year the International Society for Cutaneous Lymphomas (ISCL) hosted a scientific meeting virtually on May 1. Over 130 clinicians, scientists, and researchers attended the five hours of sessions from around the globe. It was beautiful to see the breadth and depth of the presentations and all the young researchers who presented their work. The focus of this year's meeting was **"Progress Continues – Molecular Insights into Cutaneous Lymphomas."**

While it was a very scientific meeting with many detailed presentations, below highlights a few from a layperson's view. The energy and dedication shared by those presenting and attending is inspiring. Of course, so much needs to be understood about this group of rare, challenging diseases. Knowing many devoted people are doing the hard work to figure it all out gives us all hope for a better future.

Keynote Presentation

Michael Khodadoust, MD, PhD, a researcher and clinician from the cutaneous lymphoma practice at Stanford University, presented the keynote. His presentation was titled: **"Biomarker-Guided Treatment of Cutaneous Lymphoma."**

Notable highlights from Dr. Khodadoust's presentation include:

- Many patients with aggressive, challenging cutaneous lymphomas cycle through many treatments, often with a short duration of response.
- The first biomarker for cutaneous lymphoma discovered was CD30. Many patients are CD30 negative or have low expression yet get dramatic results with targeted treatment. The question to be answered is why.
- Offered the proposal that if a patient does not express 10% or more of CD30, that individual may still have a clinical benefit of targeted therapy. This recommendation is based on what has been learned in clinical practice since the FDA approval for CD30+ targeted treatment.
- The future for seeking more genomic biomarkers is promising. What we know today:
 - » Most of the knowledge is of Sézary syndrome.
 - » The genomic landscape of cutaneous lymphomas is genetically heterogeneous, or in lay terms, all are

different from each other with no consistency in the genetic presentations.

- Given that fact, there will be no silver bullet for treating all patients:
 - » More work is needed for all variants of cutaneous lymphoma, especially for early-stage mycosis fungoides.
 - » Not a lot of genes are mutated, which tells us that there isn't a good opportunity for targeted gene therapy as is seen in other cancers.
 - » New clinical panels testing for genomic biomarkers for cutaneous lymphomas are required. Stanford is creating clinical panels and including cutaneous lymphomas, which is a start to helping with diagnosis and treatments.
 - » New opportunities to investigate current available targeted therapies which may be of benefit to some patients.
 - » Different classes of genomics may be necessary and more critical in cutaneous lymphoma

Conclusions:

- The genomic landscape of cutaneous lymphoma presents significant challenges to identifying genomic biomarkers that treatments can target.
- New tests tailored to cutaneous lymphoma are needed to characterize potential genomic biomarkers.
- Mutations occur in small patient populations, so it is hard to incorporate them into clinical trials. Still, patients should be sequenced so these individual genomic biomarkers can be incorporated into clinical trials, which will allow for data capture across a variety of clinical trial patient populations.

Quality of Life Presentations

Of particular interest was the inclusion of two quality of life presentations in the ISCL meeting. The first presentation, entitled **"A Cross-Sectional Study Examining the Diagnosis and Psychosocial Experiences of Patients with Cutaneous Lymphoma,"** was presented by the Lymphoma Coalition's Research Coordinator, Natalie Dren. Based on a research report authored by the Lymphoma Coalition and Cutaneous Lymphoma Foundation teams, it represents data captured from the Coalition's 2020 Annual Global Patient Survey.



This presentation provided the following conclusions:

- Time to diagnosis remains unacceptably long for many patients with cutaneous lymphoma (12+ months).
- Many patients with cutaneous lymphoma are not receiving enough information at diagnosis.
- Patients with cutaneous lymphoma are disproportionately affected by certain psychosocial issues specific to their disease and require more support across various areas.

The second quality of life presentation was shared by Neel Ravel, from the Washington University School of Medicine in St Louis, MO. Entitled “**Racial and Ethnic Trends of Incidence and Survival in Mycosis Fungoides/Sézary Syndrome: A SEER Analysis**”, it included the following conclusions:

- Health disparities data are limited in the literature for mycosis fungoides and Sézary syndrome.
- The US National Cancer Institute’s SEER Program (Surveillance, Epidemiology and End Results) provides information on cancer statistics to reduce the cancer burden among the US population. Within the SEER dataset, there is no socioeconomic data available for cutaneous lymphoma.
- There is an opportunity to fill this knowledge gap.
- Current population-level data pointed to worse overall survival for non-Hispanic black patients.
- Incidence is increasing significantly for non-Hispanic white and non-Hispanic black patients.
- The study was limited to a retrospective review. No data about health literacy or access to care was available to include in the analysis.
- Future study recommendations: validation of data required incorporating insurance status to reflect access to healthcare issues.

- More studies are required to include retrospective analysis of data available in other databases and capture prospective data to understand challenges in diagnosis, treatment, and access to care across patient diversity within the cutaneous lymphoma landscape.

As presented in the two quality of life studies, much more work needs to be done on the socioeconomic and psychosocial impact of cutaneous lymphoma on all individuals diagnosed, especially to understand the differences across the spectrum of race, ethnicity, and other barriers to support.

The Value of Collaborations

The topics presented at the ISCL Scientific Meeting were diverse and included genetics and the micro-environment, prognostic factors, therapeutics, and a discussion of challenging cases that covered many subtypes. Time for discussion and questions were provided after each presentation, allowing colleagues to learn about the individual discoveries being documented at various institutions around the globe. That is the great value of forums like this scientific meeting - it allows specialists worldwide to compare experiences, share valuable insights, and foster new ideas for collaborations in order to increase the understanding of the diseases. This is a critical component of scientific research sharing, especially in rare diseases like cutaneous lymphoma, where patterns are hard to find. By bringing these experts together through the International Society for Cutaneous Lymphomas, what is learned is strengthened through sharing.

Dr. Julia Scarisbrick, from the University Hospitals Birmingham (UK), shared this quote during her presentation, which sums up the importance of this meeting and those to come:

“Working together for improved research – It always seems impossible until it’s done.”

Nelson Mandela



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TIME SENSITIVE MATERIALS ENCLOSED

CUTANEOUS LYMPHOMA FOUNDATION

It's almost time to  **Get Your Move On!**
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WHO: Anyone can participate!

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WHY: Make a difference in your life, and the life of others affected by cutaneous lymphomas!

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