Cutaneous Lymphoma Foundation
FORUM

GENOMICS OF CUTANEOUS T-CELL LYMPHOMA

The whole era of understanding the genetic basis of cancer grew out of Philadelphia. Peter Nowell, Chair of the Department of Pathology at the University of Pennsylvania, along with David Hungerford, utilized a new approach to study chromosomes. Chromosomes are the cellular content around which DNA is composed. In 1959, they found out that there was an abnormality that occurred consistently in a kind of leukemia – chronic myeloid leukemia. This is important because it's the first time it was recognized that there was a consistent association between a chromosome abnormality and a cancer. It was remarkable because even 10 years earlier, the number of chromosomes we had as human beings had not been established, making this a landmark study. Several decades later in the 1990s, medicines that target this abnormality were developed and ushered in the era of Precision Medicine - thus marking Philadelphia as the birthplace of what is called "Precision Medicine."

It is important to understand the central principle - the process by which information flows from genes located in chromosomes into proteins. DNA gets transcribed to RNA which gets translated to protein and that ends up being how the function of something coded by DNA gets expressed. Today, we have very powerful tools which make it possible for us to examine the DNA of cancers in its entirety – something we weren't able to do 20 years ago.

Based on public and private efforts to sequence the entire human genome, Dr. Francis Collins, Director of the National Cancer Institute, and Dr. Craig Venter who worked in the private sector, sequenced all of the genes in our genome and found out that we have approximately three billion base pairs which encode about 25,000 genes. This spurred the question – what if we did that with cancer cells? Why should we assume that a cancer cell has just the one abnormality? What if we studied all three billion base pairs contained in a cell's DNA?

New technology – next generation sequencing was developed, which enables examination of the entire three billion base pairs of DNA in cells.

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2019 Issue 2

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.

FORUM

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Forum is published by the
Cutaneous Lymphoma Foundation.
Editor: Hilary Romkey
Layout & Design: Deb Van Zegeren

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.

The Cutaneous Lymphoma Foundation's patient educational newsletter, Forum, has been made possible thanks to the following generous supporters:

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CUTANEOUS LYMPHOMA FOUNDATION

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FROM THE BOARD PRESIDENT

Joe Eischens, Esq.

Summer greetings, Readers!

"...Investigators are busy year-round going to work for us to improve patients' quality of life..."

Joe Eischens

I hope that this summer edition of the Forum finds you in good health, and enjoying this beautiful season. I hope that you are able to use the sunshine in the most beneficial of ways, safely soaking in some of those healing rays. The Cutaneous Lymphoma Foundation is busily planning our programs for 2020, in hopes that you will join us at a live event in the near future.

While summer may be a slower time for some, we are thankful that in the field of research, investigators are busy year-round going to work for us to improve patients' quality of life through research and new therapies. This summer edition will focus on the research arena, including a look at the way research has changed and advanced over the last 20 years. Some of our most respected and seasoned medical professionals weigh in on their perspectives on research - then, now, and what's in store for us down the road.

In addition, we take a look at understanding the genomics of cutaneous T-Cell lymphoma; an area with a most exciting future for us in targeted therapy and predicting the effectiveness of treatments on patients.

As always, we are thankful for your support and encouragement. Without you, we would not be able to provide these life-changing resources for the cutaneous lymphoma community to further improve your knowledge and understanding of your disease.

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton

"The good news is there is a lot going on in cutaneous lymphoma research."

Susan Thornton

Woo Hoo - It's summer!

Not sure about you, but I always look forward to the slower pace of the summer months. For me, it tends to be a little quieter and a much needed rest from the busy spring. Hopefully you are taking time to enjoy the lazy days while reading a good book by the pool or beach.

We changed things up a bit with the theme of our Forum newsletter this time. Typically we have focused on research in our spring issue, but this year you will find it is the focus of this summer edition.

The good news is there is a lot going on in cutaneous lymphoma research. Honestly, it's challenging to keep up with everything. In our efforts to educate you on the different areas of research, we asked Dr. Kojo Elenitoba-Johnson to share his knowledge in this edition. Dr. Elenitoba-Johnson joined us at our Patient Education Forum in Philadelphia this spring and shared his perspective on cutaneous lymphoma from a genomic view. After you read this article, you might want to check out his video from that event on our website: https://bit.ly/2Yh5Hk0 (Click "Show More" to see timestamp links).

In addition, we thought it would be interesting to ask some of the clinicians who have been in the field of cutaneous lymphoma for many years to share their perspectives on the changes they have seen and their perspectives on the future. While much has

From the CEO...continued on page 7

Research Through the Years

In looking at the ways that research has changed and advanced over the years, we asked some of our most seasoned medical professionals, Drs. Youn Kim, Stuart Lessin, and Gary Wood, to weigh in on their perspective on some of those changes, challenges, and their visions for the future.

From your perspective, how has research changed in the last 20 years?

Dr. Kim: We now have a better understanding of the biologic and molecular abnormalities in MF/SS - CTCL, thus treatments can now target those specific pathways or molecules involved in the lymphomagenesis and progression. This has led to more targeted therapies where we get at the malignant cells more specifically and try to leave the good normal cells undamaged. Examples of this are the brentuximab vedotin and mogamulizumab approvals, where we target proteins more expressed on malignant vs. non-malignant T-cells.

We have also seen huge progress in immune therapies, that is how we can boost our immune system to attack the cancer cells better. Just as in melanoma, where checkpoint inhibitors have unleashed the good T-cells to fight the cancer cells, we have seen similar approaches and developments in CTCL. The trick is to jazz up the healthy T-cells without worsening the malignant T-cells. But great progress is ongoing and the T-cell or macrophage targeted immune therapies are effective or being studied in CTCL.

Combining potential great therapies is also important and we have seen lots of progress in learning how to combine treatments to results in synergistic outcome and without additive side effects. Finally, the amazing progress in cutting edge technology in human diseases, including cancer, has resulted in using these tools to understand CTCL as well, helping us develop better therapies. Not only more targeted for cancer +/- jazz up immune system, but promising advances are ongoing to personalize therapies better by applying new targeted/actionable next generation sequencing tools on patient's samples.

Dr. Lessin: The number of new therapies being developed and tested has increased.

Dr. Wood: New technologies such as high-throughput sequencing, multispectral imaging and nanostring technology have allowed us to perform studies that would have been difficult or impossible to do previously. Clinical trials now include many studies of highly targeted therapies rather than broad acting agents.

What did we learn in the last 20 years; what did we learn today that we didn't know 20 years ago?

Dr. Lessin: We learned that immunotherapies remain a powerful treatment approach.

Dr. Wood: On the basic research side, we now know much more about cytokines, T-cell subsets, immune regulatory networks and the mutational landscape of CTCL. On the clinical side, large-scale collaborative efforts are defining prognostic factors that complement the traditional clinical staging of patients. We also know that in appropriate cases, patients will respond well to lower doses of radiation therapy than previously believed.

What do you see are the challenges we are still facing in research? What do we still need to know?

Dr. Lessin: The challenges are to further define the immune checkpoints to turn off the disease and develop maintenance therapies that can increase disease-free and overall survival in advanced stage disease.

Dr. Wood: Despite important advances in therapy that are improving patient outcomes, we still see the emergence of treatment resistance in many cases. We need to better understand the mechanisms underlying this challenge.

What would your vision of research be? If you could see the future, what would it look like?

Dr. Kim: MF/SS-CTCL is one of THE most heterogeneous and rare diseases we know, thus we cannot use a "one-size-fits-all" approach and do not even have uniform frontline agents – each patient must be managed with tailoring of treatment best for that patient. Stanford just presented early data on personalized/precision management in MF/SS at the SID meeting, and we believe this is the future! There is still a lot of work to do still to validate and refine; the more we learn about the biologic and molecular mechanisms of CTCL, the better we can target and personalize/be precise with our treatments in the future.

Dr. Lessin: I see a greater role of personalized or precision medicine being applied to cutaneous lymphomas so that individuals can be identified who will be treated with treatments tailored for best results and outcomes.

Dr. Wood: Most prior research has focused on analysis of whole tumor samples. Although very informative, this approach does not capture important differences among individual tumor cells—differences that might be responsible for the emergence of treatment resistance after an initial good response. Future studies will include single cell analytics that allow us to see the true diversity of tumor cell abnormalities that exist in a given patient at a given time. This type of precision medicine will allow the design of personalized treatment plans with greater specificity than previously possible. However, we also need to focus on therapies that kill tumor cells quickly so they do not have time to undergo further mutations leading to treatment resistance.

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My Mom's Journey with Sézary Syndrome

Shared by Mike G.

I'll never forget the sage advice a doctor shared when he told us for the first time nearly four years ago that my Mom, Madeleine, had Sézary syndrome, a Stage IV type of cutaneous lymphoma, in her blood, lymph nodes, and skin: "This journey is going to be like a roller coaster ride, with plenty of ups and downs and twists and turns. Try not to let your emotions get too high or too low along the way." That was very valuable advice.

At that moment, as I became one of Mom's caregivers, I began to think about how we could move from being afraid to being empowered. I wanted to learn as much about the disease and treatment options as possible, so I visited the Cutaneous Lymphoma Foundation's website, researched treatment options and clinical trials, and also found some online support groups for patients and caregivers.

I contacted some Sézary syndrome patients by phone and email to inquire about their experiences with some of the treatments and clinical trials, as well as some patients who had stem cell transplants. One of the clinical trials that piqued my interest was a Phase 3 trial with mogamulizumab, a monoclonal antibody that seemed to be effective in dramatically reducing the amount of cancer in some Sézary syndrome patients during the Phase 1 and Phase 2 trials. I tracked down and spoke with a few patients who were in the Phase 3 mogamulizumab trial and who thus far had been experiencing a favorable response to that treatment.

Meanwhile, just a few days after being diagnosed, mom's skin flared and she felt a burning sensation on the skin over her entire body that she described as "like being inside an inferno." We called the hospital and scheduled an emergency meeting with an oncologist for the next day. At that meeting, the doctor provided mom with a prescription to help alleviate the immediate pain, and indicated that a more aggressive treatment was in order.

The doctor suggested an approved treatment called romidepsin. We asked her about the mogamulizumab clinical trial and she responded that she had seen some great responses among Sézary syndrome patients in the Phase 2 trial and that if mom qualified for the current trial, it would be worth trying to get her into it; that was a potentially life-changing decision.

"This journey is going to be like a roller coaster ride, with plenty of ups and downs and twists and turns. Try not to let your emotions get too high or too low along the way."

A few weeks later, mom was approved to join that trial and we were very excited! The mogamulizumab infusion was uneventful and took about an hour, as was the "watch and wait" follow-up period at the hospital, during which time Mom was comfortable and ate a sandwich.

But 25 minutes into a 30-minute ride home from the hospital, the roller coaster ride took an unexpected turn, when she had an infusion reaction. Suddenly, Mom felt excruciating pain in her hips, extreme chills, nausea, headache, and a fever. Apparently, the infusion and Mom's immune system were working together to kill much of the cancer in her body very quickly. I pulled the car to the side of the road and called an ambulance. Riding in the back of the ambulance with my mother to the hospital, I was texting with another patient in the trial who had a nearly identical reaction to her first infusion with mogamulizumab, and who subsequently responded very well to the treatment. I shared with my Mom in real-time the reassuring encouragement and experience this other patient was relaying to us.

With the help of some amazing doctors, mom's infusion reaction was resolved within about an hour, and incredibly, nearly 80 percent of the cancer in her blood was gone! She was admitted overnight to the hospital for observation, and the next day, she looked and felt great.

Unfortunately, the clinical trial protocol stipulated that participants who have a reaction that requires admittance to a hospital can no longer remain in the trial. We were devastated! We reached out to Susan Thornton, the CEO of the Cutaneous Lymphoma Foundation, and she provided incredible moral support and reached out to the sponsor of the trial on our behalf to see if there were any other ways Mom might still be able to receive the treatment (e.g. on a Compassionate Use basis outside the trial), but that was not to be.

A couple of weeks later, the doctor recommended Mom try the romidepsin – and within about eight weeks, Mom achieved a complete remission that she has enjoyed to this day – nearly three-and-a-half years later! What a ride it has been.

Through my experience, I became more engaged with the Cutaneous Lymphoma Foundation and now produce a live streaming monthly talk show on Facebook and YouTube with Susan Thornton to educate other patients and caregivers about treatment options and other forms of support so they too can be empowered. We've learned there is much to be hopeful for, with many new treatments emerging, and through the support of the Cutaneous Lymphoma Foundation and fellow patients and caregivers.

CLF Welcomes New Board Member

In June, the Cutaneous Lymphoma Foundation (CLF) welcomed David Elefant to its Board of Directors.

An active member of the cutaneous lymphoma community for many years, David has been involved with both the MF-Listserv and the Foundation since its beginning.

As a board member, he plans to focus his efforts on fundraising so the CLF can continue and improve the services it offers cutaneous lymphoma patients and their families.

To learn more about David, visit our website at www.clfoundation.org/board-of-directors.

From the CEO...*continued from pg 3*

been accomplished, there is still so much more that we need to learn.

In light of that, we are announcing a new grant program to fund cutaneous lymphoma research. The Cutaneous Lymphoma Catalyst Research Grant was announced on August 1. We shared more details about our focus on supporting research in our **Research Report: The Impact** that was mailed earlier this summer. With the success of our CLARIONS grant program and our continued support of Young Investigators in cutaneous lymphoma, we've supported close to $500,000 in research grants. For a small, rare disease community, that's a big deal. Our commitment to continue funding important research initiatives would not be possible without your support. Stay tuned for more information about our research funding. You can learn more here: https://www.clfoundation.org/clf-funded-research.

I would be remiss if I did not mention our big event to raise awareness and funds celebrating World Lymphoma Awareness Day (September 15) and Blood Cancer Month (September). **We're In This Ride Together** is our virtual signature cycling event. You can participate by riding your bike (on the road, in the gym or at home), supporting other participants or teams (including the CLF staff team) or by helping to get the word out via your social media channels. Join us as we let the world know about cutaneous lymphoma! Watch your email for announcements and notifications on how you can participate.

We've got a great Fall planned with live educational programs in Kansas City (Missouri), Milwaukee (Wisconsin) and Framingham (Massachusetts), along with our monthly Facebook/YouTube Live interviews. If you can't make it to our educational programs, you can always check out the post-program videos on our website.

Our mission is to serve you and meet your needs. Let us know how we can do that better. We are always listening and incorporating your feedback.

Enjoy the rest of your summer!

Genomics...*continued from pg 1*

Today, we can use whole genome sequencing to confirm the presence of abnormalities, and confirm the complexity of cancer genomes. This definitely shows us all types of DNA abnormalities, including translocations, deletions, amplifications, and point mutations. We are given opportunities through this technology to try and personalize the treatment, or use precision therapy that we know inhibits the specifically mutated proteins that are critically involved in the origin of the disease.

This new technology is beginning to yield previously unknown insights in all cancers, including cutaneous lymphoma. We now have a genetic classification for a large number of cancers. What we are trying to do now with research is to use less invasive methods to be able to get at the tumor DNA. For example, to take blood and analyze the DNA so patients won't have to have as many invasive procedures to be able to pick up their disease. In the future, the goal is to develop predictive biomarkers for response to specific therapies. Right now, we don't know who is going to respond to a particular kind of treatment. So a question we could ask: are there genetic or non-genetic signatures that say if you have this signature, you will respond to a particular "X" drug. This would occur prior to the treatment, so the effective rate could be dramatically increased, rather than treating patients with expensive treatments, not knowing whether or not they will respond.

In conclusion, if you perform genomic analysis, you learn more about how the disease develops. For example, it can take on average six years for a conclusive diagnosis of cutaneous lymphoma to be established. Imagine if we were able to make the diagnosis in year one, with the help of diagnostic markers. The most profound effects on outcomes that we have seen have been linked to early detection, or prevention. If we can identify diseases earlier, we will be able to treat them more effectively.

You have taken a step forward by participating in the cutaneous lymphoma community and educating yourself about the disease and the research going on to improve diagnosis, treatment and outcomes for patients. We've made great strides and there is so much more to learn. With new technology, we hope to increase our understanding of this complex disease and truly move into the age of Precision Medicine for everyone diagnosed with cutaneous lymphoma.

Patients can help with this research. By being curious, asking about and participating in clinical trials, patients can facilitate research that may end up being generalizable to a larger number of people. Studies are more effectively done with patients who are actively involved in their care and in the advancement of research of the disease(s).

Kojo Elenitoba-Johnson MD
Peter C. Nowell, M.D., Professor
University of Pennsylvania Perelman School of Medicine
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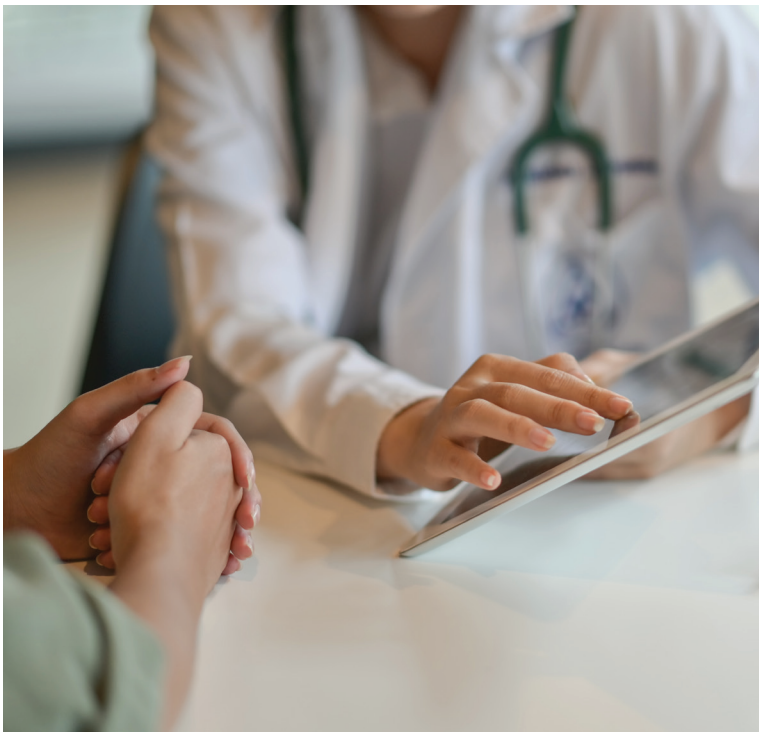
Director, Division of Precision and Computational Diagnostics

CLINICAL TRIAL UPDATE: Trillium Therapeutics Inc. TTI-621-02 Trial

A clinical trial to test an investigational drug, TTI-621, for the treatment of relapsed or refractory percutaneously accessible solid tumors and mycosis fungoides (a form of cutaneous T-cell lymphoma) is actively recruiting patients.



This TTI-621-02 trial is open across the United States. In this study TTI-621 is administered directly into the tumor or skin lesions (intralesional injection). TTI-621 is designed to block a protein called CD47, which is present on cancer cells and is used by cancer cells to hide from the body's immune system. Blocking CD47 with TTI-621 may help the body's immune system find and destroy the cancer cells.

Based on data from 27 patients with relapsed/refractory mycosis fungoides/Sézary syndrome who were treated with TTI-621 in this trial, intralesional injection of TTI-621 was well tolerated, with no serious treatment-related adverse events. Reductions in treated lesions were observed in 91% of patients, with 41% observing significant lesion improvement.

This study is currently recruiting patients. For more information, including a list of trial locations, please refer to ClinicalTrials.gov website.

CATALYST FOR CUTANEOUS LYMPHOMA

The Cutaneous Lymphoma Foundation (CLF), with support from the Leukemia & Lymphoma Society (LLS), is pleased to announce the inaugural year of the **Cutaneous Lymphoma Catalyst Research Grant**, a new funding initiative exclusively for cutaneous lymphoma research.

The CLF's mission is to support every person with cutaneous lymphoma by promoting awareness and education, advancing patient care, and facilitating research.

To help achieve this mission, the Foundation's new Research Awards Program (RAP) is designed to help further efforts of researchers conducting innovative cutaneous lymphoma research while they investigate the causes and improve treatments, and clinical care and quality of life for patients. Discovering new avenues for better therapies and, one day, a cure for cutaneous lymphoma are key aims of this program.

SKINCARE CORNER Q&A

What is the difference between exfoliative erythroderma and exudative erythroderma for non-medical people?

Erythroderma means 80-100% of the total skin surface has a generalized redness or erythema with variable degrees of scaling. Many patients complain of fever, chills, shivering, and malaise. There are multiple causes including drugs, chronic skin diseases such as psoriasis, atopic dermatitis, contact dermatitis, cutaneous T-cell lymphoma and other lymphoreticular malignancies.

Exfoliative erythroderma refers to erythroderma with severe scaling and extreme loss of skin and "shedding like snow." Exudative erythroderma means generalized redness of the skin with swelling or edema and oozing of fluid. It can be indicative of secondary skin infection due to the interruption of the normal skin barrier. Erythroderma can be both exfoliative (scaling) and exudative (moist with fluid from the tissue).

How can a patient/caregiver best treat/deal with each condition?

Patients with acute onset often require hospitalization for frequent monitoring of fluids and electrolyte balance, heart failure, and nutritional needs.

If the condition is more chronic some suggestions for homecare:

1. Frequent lubrication of skin with bland emollients such as Vaseline, Aquaphor, Vaniply (all over the counter).
2. For more exudative erythroderma, apply wet dressings or clothing. Change every 2 hours. May use cotton pajamas with long sleeves and pants and saturate with tap water and place in dryer for 5-10 minutes to warm up.
3. To help reduce infections, take a bleach bath every 2-3 days. Put ½ cup of household bleach in a full tub of water and soak for 10 minutes. Do not submerge head and avoid eye contact. Rinse off with tap water and then apply lubrication.
4. Avoid sun exposure and when going outside cover up and wear sunglasses
5. For areas of intense itching apply intermittent ice packs or use balloons inflated with water and add a teaspoon of rubbing alcohol and put in freezer. The balloons are quite malleable and can be reused.
6. Raise the room temperature by 3-5 degrees to avoid chills. Patient with erythroderma lose his/her ability to maintain body heat.

Elizabeth McBurney, MD, FACP
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You can find more Skincare Corner Q&A's on our website at: www.clfoundation.org/skincare-corner-qa

Information researched and compiled by:
Meredith deH. Haab, Ed.D.

CUTANEOUS LYMPHOMA PATIENT EDUCATIONAL OPPORTUNITIES

UPCOMING 2019 EVENTS*

SEPTEMBER 19: KANSAS CITY, MO
Cutaneous Lymphoma Foundation
Answers From the Experts...Live!

OCTOBER 19: MILWAUKEE, WI
Cutaneous Lymphoma Foundation
Patient Educational Forum

NOVEMBER 2: FRAMINGHAM, MA
Cutaneous Lymphoma Foundation
Patient Educational Forum

For more information and to register for CLF events, visit www.clfoundation.org or call 248.644.9014, ext. 4.

** Dates and venues are subject to change. Please check the website for detailed information.*

The Cutaneous Lymphoma Foundation offers free educational programs throughout North America providing an opportunity to:

- Receive the latest information about cutaneous lymphoma and learn about treatment options from experts in the field.
- Learn what's new in cutaneous lymphoma research and clinical trials.
- Have questions answered about the different types of cutaneous lymphoma, treatments, and daily living. The Q & A sessions provide an opportunity to ask in a relaxed and friendly environment.
- Meet and network with other individuals affected by cutaneous lymphoma. Meet others who know and understand what you are going through.
- Learn about available resources for treatment and support.

We hope to see you at a program soon!

PATIENT NETWORKING GROUPS

The Cutaneous Lymphoma Foundation also offers patient networking groups in the following cities. Visit our website for more details on meeting times and locations.

CLF-BOS
Boston, Massachusetts
www.clfoundation.org/CLF-BOS

CLF-DC
Fairfax, Virginia
www.clfoundation.org/CLF-DC

CLR-LV
Las Vegas, Nevada
www.clfoundation.org/CLF-LV

CLF-OR
Portland, Oregon
www.clfoundation.org/CLF-OR

CLF-SLC
Salt Lake City, Utah
www.clfoundation.org/CLF-SLC

CLF-TPA
Tampa, Florida
www.clfoundation.org/CLF-TPA

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BIRMINGHAM, MI 48012

TIME SENSITIVE MATERIALS ENCLOSED

Thank you for helping us make a difference at the Cutaneous Lymphoma Foundation!

Your support has a tremendous impact on our ability to make a difference in the lives of those affected by cutaneous lymphoma.

Your support allows us to provide quality information via programming and free publications.

Your support provides assistance in identifying beneficial care and treatment options in response to email and phone inquiries.

Please continue to support the Cutaneous Lymphoma Foundation by making a donation today using the enclosed envelope or via our website *www.clfoundation.org/giving-online*