



GRACE: GROWING RESILIENCE AND COURAGE™

A serious medical condition, including cutaneous lymphoma or any cancer diagnosis, often has many ups and downs, unknowns and fears. Distress or sadness, questions and concerns, are commonplace when facing a disease that may alter the way we see the world around us, or even our identity. Straddling the highly technical realm of cutting-edge treatments from hematology/oncology with the more intangible aspect of healing from a serious illness was an impetus to developing the GRACE (Growing Resilience and Courage™) program.

GRACE was designed to bridge this gap, to help illuminate key elements that may contribute to a “healing” process. Doctors and the dazzling discoveries in medicine endeavors to cure us, and it is humbling to see the remarkable advances taking place within medicine. Yet the existential aspects of healing often elude traditional medicine.



The GRACE program was our attempt to answer some of these fundamental questions about healing:

- How can discovering meaning and purpose help us rise above our challenges and support our healing process?
- How do we manage perspective—in an authentic way that enhances our well-being?
- How can we cultivate resiliency when facing a serious medical illness? How can we manage fear? Especially at a time for a new scan, blood test, or doctor’s visit?

DISCOVERING MEANING AND PURPOSE

Dr. Viktor E. Frankl’s 1959 classic work in his book, *Man’s Search for Meaning*, may be one of the best known vehicles to contemplate meaning and purpose and the power of perspective-making life experiences. Frankl’s key concern was how anyone at all survived the terrible conditions of the concentration camps. He admiringly quotes the words of Nietzsche: “He who has a Why to live for can bear almost any How.”

Frankl posited that those who could see beyond the suffering within the concentration camp by find-
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CUTANEOUS LYMPHOMA FOUNDATION

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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.

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.

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



FROM THE BOARD PRESIDENT

Laurel Carlson



"Each of us needs to become empowered so that we can be active participants in our care."

Laurel Carlson

Happy Spring! For many of you, this is the time of the year when your world becomes warmer and more colorful. For me, living close to Washington, DC, the cherry blossoms alert us that spring has officially arrived. However, in the spring of 1983 I received my mycosis fungoides diagnosis, and as pretty as the blossoms probably were that year, I was too consumed with my life-changing news to enjoy them. Like many of you, I was faced with the challenge of finding someone who was familiar with this strange disease. At that time, there was no Cutaneous Lymphoma Foundation (or even Google!) to give me guidance or any idea of what life with this disease would be like.

This issue of the Forum focuses on patient-centered care, a very important topic for all of us who spend a portion of our lives receiving treatment. In the years since my diagnosis, I have seen several doctors. Some of them had only limited familiarity with my disease, and although that was not very reassuring to me, it did encourage me to learn as much as I could about my disease and advocate for my care whenever possible. Fortunately, my disease has been manageable and I was not faced with some of the challenges that you might be. However, patient-centered care is relevant and applicable no

From the President...continued on page 7

BOARD OF DIRECTORS NEWS

The Cutaneous Lymphoma Foundation wishes to thank Joe Eischens for his gracious leadership and service as he steps down from our Board of Directors. Joe joined the Board of Directors in 2012, and humbly became President of the Board in 2016 and served in that role until Fall 2019.



While president, Joe focused on fundraising so the Foundation could continue to provide a broad range of services and information, along with renewed effort toward advocacy at all levels of government, and creating partnerships with researchers in the medical field so that one day a cure will be found.

Thank you, Joe, for your dedication to our community and for your servant leadership.

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton



"The best thing to hold onto in life is each other."

Susan Thornton

We are living in interesting times, to say the least. By the time this Forum reaches your mailbox, we will have, I hope, gotten through one of the most challenging times collectively faced around the globe. It has shaken us to our core and provided an opportunity to look at everything we do through a new lens.

We have had to quickly modify our in-person programs to reflect compliance with emerging guidelines for safety. If you are on our email list, you will have seen our announcement moving the spring in-person educational programs to an online format and/or rescheduling later in the year. We appreciate your understanding and hope that you were able to join us for the online programs.

I would be remiss if I didn't add thanks to the entire Foundation staff who stepped up and worked hard to reorganize our programs so they could still be delivered, and to all the incredible healthcare providers who graciously worked with us to bring their expertise to you in an online format.

From the CEO...continued on page 7

UNDERSTANDING THE DIAGNOSIS PROCESS - PART 2

In the last issue of the Forum, we explored biopsies as the first step in the diagnostic process for cutaneous lymphoma. In this issue we take a closer look at the ancillary tests that are part of the diagnostic process: immunohistochemistry and molecular testing (flow cytometry, clonality analysis).

IMMUNOHISTOCHEMISTRY

Dermatopathologists (pathologists who analyze skin samples) use a method called immunohistochemistry to identify markers (antigens) in a tissue sample using a panel of antibodies. The antibodies look for the different proteins on the surface of the cell to identify what kind of cell they are. These surface marker proteins are often named CD, or “Clusters of Differentiation,” followed by a number.

Some proteins are only expressed on T-cells and some only on B-cells. For example:

- CD19 and CD20 = B lymphocytes
- CD3, CD4, CD8 = T lymphocytes (typical in MF)
- CD30 proteins characterize lymphomatoid papulosis and anaplastic large cell lymphoma.

Identifying these markers can aid in both the diagnostic process and in determining treatment.

MOLECULAR TESTING

Molecular testing generally includes tests done to evaluate genetic aspects of samples, such as DNA or RNA. Insights through molecular testing can help support a cutaneous lymphoma diagnosis. Molecular testing includes flow cytometry and clonality analysis.

FLOW CYTOMETRY

Blood work (labs) are also part of the diagnostic process for cutaneous lymphoma. Labs may include:

- CBC (complete blood count) - which evaluates all of the components of blood (white blood cells, red blood cells, and platelets) and can tell if there is an increased or decreased number of lymphocytes in the blood;
- LDH (lactate dehydrogenase) - which may be elevated if there is a high number of cancer cells or abnormalities in lymph nodes or other organs; and,
- Flow cytometry - which counts and sorts lymphocytes to tell if there are abnormalities in the bloodstream

What is flow cytometry?

It is cell (cyto) - measurement (-metry) as cells move in a stream (flow) past a set of stationary detectors.

What happens in flow cytometry?

A blood or tissue sample is taken and is spun down to concentrate the cells. A liquid culture medium is added to separate the red blood cells from the white because the focus is on the white blood cells. The white blood cell sample is divided into different tubes and antibodies that are being targeted are added to the appropriate tube. The tubes are put into an analyzer where the cells are forced to be ejected in a single file so that each cell can be analyzed by a laser and detector. The detector translates the information into histograms (a graphical display of the data) which identifies the markers on the cell and sorts them based on the proteins they express.

Specialized pathologists (hematopathologists) analyze the histograms for any abnormalities, and depending on the graphical display, together with input from the physician viewing the patient’s skin, identify the potential cutaneous lymphoma variant.



CLONALITY ANALYSIS

We can think of cancer as uncontrolled growth (or runaway clone) of any one cell that continues to multiply until it gets to be a size that is detectable. In the case of cutaneous lymphoma, it may be a T or B-cell. If a marker on the cell can be identified and it shows that all the cells in a biopsy came from one original cell, it can be a sign of cancer. It is important to remember that clonality is supportive of a diagnosis but not diagnostic because other things (like inflammation) can also give you that same positive result of clonality but not be a cancer.

A TCR (T cell receptor) gene rearrangement study searches for clonality. A T cell receptor is a molecule on the surface of T cells that is responsible for binding to parts of viruses and

other abnormal cells and activating the immune system to destroy them. T cells all have slightly different receptors so they can identify many different things; clones, however, all have exactly the same receptor. Gene sequencing, or high throughput sequencing, is a newer technique that may also be used to evaluate for clonality in skin, blood, or other tissues.

Diagnosis of cutaneous lymphoma is not based solely on a pathology report or blood tests. Cutaneous lymphomas require clinical and pathologic correlation - there is a need to see what the skin looks like and how it behaves, and a history of what that “skin rash” is doing (dermatology), plus the pathology to reach a proper diagnosis.

REFERENCES:

The content for this article was provided from the event recordings related to diagnosis and pathology listed below.

Final article review was provided by Cutaneous Lymphoma Foundation’s Medical Advisory Council.

For a fuller understanding, we encourage you to watch the following videos:

2019 Milwaukee PEF – Diagnosis and Staging Cutaneous Lymphoma
Keri S. Chaney, MD, Wisconsin College of Medicine
Link: <https://bit.ly/2Pltg5y>

2019 2-Day Patient Conference - Clinical Panel Q&A
Craig Okada, MD, OHSU Knight Cancer Institute
Link: <https://bit.ly/2S4al0f>

2016 - 2017 2-Day Patient Conference: Cutaneous Lymphoma Overview
Ellen Kim, MD, Perelman School of Medicine
Link: <https://bit.ly/39ciV2v>

2016 2-Day Patient Conference - Pathology of Cutaneous Lymphoma
Alistair Robinson, BSc (Hons), MBChB, FRCPath and DipDermRCPATH, Lisbon Institute of Oncology
Link: <https://bit.ly/2GW4Yd9>

2016 Los Angeles PEF - Node Pathology and Flow Cytometry
Sherif Rezk, MD, UC Irvine Medical Center
Link: <https://bit.ly/2We9KJB>

In Memory of Dr. Glen Bowen

The Cutaneous Lymphoma Foundation is deeply saddened to say goodbye to Dr. Glen Bowen of the Huntsman Cancer Institute. Dr. Bowen passed unexpectedly in February, 2020.



Dr. Bowen worked tirelessly in the battle against cancer in his role as clinician, Professor of Dermatology and the Clinical Director of the Multidisciplinary Cutaneous Oncology

Program. Dr. Bowen will be deeply missed, though his devotion to cutaneous lymphoma patients will be forever remembered.

Lymphoma Coalition Survey: Together We Exceeded Our Goal - Thank You and Congratulations!

Thank you to everyone who participated in the Lymphoma Coalition's 2020 Global Patient Survey on lymphoma and CLL!

With your help, we met and exceeded our goal of 400 respondents!

A total of 525 members of the cutaneous lymphoma community responded to the survey. Of those, 470 were individuals who have the disease and 55 were caregivers.

Through this survey, patient experience in lymphomas as well as the impact of treatment and care can be better understood, and Lymphoma Coalition and its global members, including the Cutaneous Lymphoma Foundation, can bring the patient voice forward.

We look forward to sharing the full survey results with you once the Lymphoma Coalition publishes their reports.

EVERYONE WILL RING THE BELL: MY JOURNEY WITH CUTANEOUS LYMPHOMA

Shared by Sabrina F.

April 8, 2019, the day that mycosis fungoides or cutaneous T-cell lymphoma (CTCL) became a part of my identity, knowledge and strength. My name is Sabrina and at age 22 I was diagnosed with the orphan disease known as cutaneous lymphoma. I currently live in New York City, but my hometown is Woodbridge, Connecticut.



“Living with CTCL has changed my life, not for the worst but for the better.”

Sabrina

Since 2016, I had a consistent rash that dermatologists kept diagnosing as “dry skin,” “eczema” or “dermatitis.” I accepted this answer for 2.5 years until my rash started to hurt, badly. Simply, clothing would hurt. I finally went to a dermatologist in NYC that gave me another eczema diagnosis and treated it with a laser that ultimately burned my skin; leaving me with bleeding blisters for weeks. After 5 biopsies, this “eczema” was something I had never heard of or thought imaginable, cutaneous lymphoma. I was diagnosed by a specialist at Yale New Haven Dermatology, “Stage 1 Mycosis Fungoides 10% of my body.”

A PART OF MY ROUTINE

I first started with phototherapy three times a week. I would use my lunch break for treatments, always being asked “Why don’t you eat lunch with us anymore, Sabrina?” Each day was not only a day of treatment but a day where I had to make up excuses of where I was and why I wasn’t with my team during lunch. The disease interrupted my social life, making me tired afterwards and leaving me with the smell of burning skin. The smell at work would remind me of the phototherapy that is, and will be, a part of my routine. Seven months later, the cutaneous lymphoma on my left foot was not responding to phototherapy. I was referred to radiation oncology for radiation treatment.

The first day of radiation I was scared, of course, but I had a smile on my face. I talked to the technicians and asked a million questions: “What does this do?” “How about this?” They had to give me a little tattoo on the bottom of my foot to make sure they put the radiation on the exact spot every time. So now I tell my family, “I have a tattoo,” even though you need a microscope to see it.

ENTERING WITH A SMILE

The technicians would have Taylor Swift playing on repeat for me as I walked into every treatment, so I could sing to my favorite songs as I lay on the table. I was once asked, “How do you walk in here with a smile every time?” My response: “If I show I am upset it makes it worse. This is just an obstacle I am faced with and will overcome. I believe everything happens for a reason and there is a reason I am faced with this.” My last treatment, I rang the bell at 7:30 pm on a Friday night. I heard clapping from patients as they came up and hugged me. As I walked out, I told each of these patients that you too will ring the bell. I left as I entered, with a smile.

WE ARE ALL THERE WITH YOU

Living with cutaneous lymphoma has changed my life, not for the worst but for the better. When I am sick, I know to check my lymph nodes. When it is sunny outside, I know to get natural sunlight for 15 minutes without sunblock. After showering, I know to moisturize; and on days of treatment



to moisturize afterwards. Though diagnosed with a chronic illness, I believe that everything happens for a reason. I write my story so that those who are young, old, or a family member know that you aren’t the only one diagnosed. We all are there

with you running to phototherapy, radiation, moisturizing every second we get and checking our lymph nodes with those monthly blood work checkups.

The Cutaneous Lymphoma Foundation has helped me come to terms with my disease and to understand it as a part of who I am, not a disease that controls me or am embarrassed about. At first, I only told my family and three best friends. Now, I am training and running the NYC Half Marathon on March 15th to raise awareness for cutaneous lymphoma affiliated programs. The advice I have for patients is to ask questions, read new research, and to simply put a smile on your face. Just like me, you the patients of cutaneous lymphoma will ring that bell, whether to end radiation or to enter remission. No matter the stage, we are never alone.

From the President...continued from pg 3

matter what stage or level of involvement your disease might be. Each of us needs to become empowered so that we can be active participants in our care.

It’s 2020, and there are many more resources available than there were for me in 1983. When a patient is diagnosed today, they are able to find multiple sources of information on the Internet. But, as you process all of this information, please don’t forget to include your medical professionals. Make sure that they listen to your concerns and questions about the information that you may have received from other sources. It is important that your health care professionals provide effective communication, empathy, and a feeling of partnership with you; but in order to accomplish this, you must share all of your concerns with them. We know that patient-centered care improves patient care outcomes, which makes it a win-win situation for both you and your health care professionals.

From the CEO...continued from pg 3

Okay. Taking a deep breath and highlighting the juicy articles in this issue. If you have ever had questions about the diagnostic tests that are done, make sure to read the second article in our series “Understanding the Diagnosis.” It’s informative. You can refer back to the first article published in the fall edition on our website: <https://www.clfoundation.org/forum>.

GRACE: Growing Resilience And Courage™ by Drs. Asher, Wertheimer, and Bronwen Jones gives a peek into the ways we might look at our disease journey through a new perspective. Given the long-term nature of cutaneous lymphoma, learning a different way of managing the ups and downs may help you work through challenges as they present themselves.

It’s a pleasure to introduce you to Sabrina, who is our patient story in this issue. I had the honor and delight of meeting her in New York City on a stormy night last fall. She embodies resilience. Enjoy her story and know that you have the power of resilience within you too.

As I’ve said to the team, remember, we are all in this together. Know that we are here for you and your loved ones, no matter

what the external world might throw at us. I’ll leave you with this quote by Audrey Hepburn:

“The best thing to hold onto in life is each other.”

Keeping you in our hearts as we navigate the waves of change together.

Take good care of yourself.

GRACE...continued from pg 1

ing some meaning in their suffering, were much more likely to be resilient. Frankl appreciated three fundamental sources for humans to find meaning: in work (which could include volunteering/service), through love and caring for another, and in creating courage during difficult times. Frankl believed these three pillars can provide an opportunity for all of us to find deep meaning and purpose in life, which he viewed as the greatest task for any person.



Leveraging the insights of Brother David Steidl-Rast, evidence and our experience have shown that 4-6 weeks of daily gratitude journaling (only 2-3 minutes a day) can provide very meaningful changes in how we perceive the world while inviting us to see the opportunities in our circumstances, even the ones that may be painful or difficult. He states that even in difficult situations there are opportunities to learn, teach, and grow, and life gives opportunities to enjoy the world around us, and learning mindfulness strategies strengthen this skill.

GRACE is a 6-week program that strives to begin to answer some of these profound questions by providing validation and practical tools to manage distress. This brief article highlights a few of these strategies. The program involves packaging some of the inspiring thinkers, writers, and speakers who embody these key ideas. The philosophical foundation of the program may best be described by physician and author, Dr. Rachel Naomi Remen: “While cure is a possibility for some, healing is a possibility for all.”

To learn more about the GRACE program at Cedars-Sinai Samuel Oschin Comprehensive Cancer Institute, visit <https://ceda.rs/2UOLDRI>

MANAGING PERSPECTIVE

Frankl was recognized for a classic truth that he learned from his harrowing experience as a Holocaust survivor: “Everything can be taken from a man but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way.” This powerful belief reminds us that managing perspective, albeit incredibly difficult at times, is a freedom that we always retain. It is a reminder that a medical diagnosis does not ultimately define our identity, our values, our behavior, and how we respond to any particular situation.

The GRACE program provides tools to learn how to manage perspective in a way that avoids being a Pollyanna (i.e. “everything is perfect”), but provides authentic strategies to enable one to see our environment and situation in a way that can be empowering. Dr. Rachel Naomi Remen reminds us that: “often people with chronic illness may become trapped and invalidated, not by the force of their disease but by their beliefs about it.” Techniques include fundamentals of cognitive behavioral therapy, mindfulness exercises, and tailored readings.

CULTIVATING RESILIENCY

One key secret to resiliency is experiencing gratitude on a regular basis and learning that life does not need to be perfect to experience gratitude. (Indeed, it seldom is perfect).

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Stay connected! Subscribe to the Cutaneous Lymphoma Foundation's YouTube channel (CutaneousLymphomaFnd) and follow us on Facebook and LinkedIn.

Rare Disease Week 2020

Rare Disease Week on Capitol Hill brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. Below is a brief summary of the week’s events and the Cutaneous Lymphoma Foundation’s participation as your representative.



FDA RARE DISEASE DAY 2020

Supporting the Future of Rare Disease Product Development

Laurel Carlson (pictured above on left), patient and President of the Cutaneous Lymphoma Foundation’s Board of Directors and Deb Van Zegeren (on right), Foundation staff member, attended the Food and Drug Administration's (FDA) public meeting on Rare Diseases on behalf of the Foundation. The focus of the meeting was the importance of patient natural histories and registry data in advancing rare disease research and rare disease product development.

Natural Histories/Registry Data

Natural histories are the gathering of clinical data related to the clinical course, presentation, and progression of a disease, in this case rare disease. The information may be retrospective (e.g. chart review, medical records), cross sectional (i.e. looking across different existing data), or prospective (i.e. collection of pre-determined data related to a study – patient registry).

Registry data is provided by patients and is related to their personal experience of the disease and/or treatment outcomes.

The value of both natural histories and registry data is what it can tell about the disease. It can define the disease course or progression, its complications, its diversity or heterogeneity, and the burdens of its treatment. It can also help inform

the design of clinical studies, outcome assessment tools and biomarkers, and help develop and improve drugs for rare diseases.

Rare Disease Product Development

In the last year, 60% of the new drugs introduced were developed for rare diseases. The FDA’s excitement about furthering rare disease research and developing treatments was palpable throughout the day. While the number of new drugs is encouraging, there are still many challenges related to manufacturing treatments for rare diseases such as how to create high quality products efficiently, and how to keep them affordable and still commercially viable and sustainable.

Individualized medicine was also discussed and the promise it holds for rare diseases that impact very small groups of patients, even a single patient. The challenge is how clinicians/researchers use these individualized tools to scale what they have learned to impact a broader population.

Another issue recognized by the FDA related to product development is the need to work globally rather than reinventing the wheel within each country. Breaking down regulatory barriers between countries means better treatment for all who are impacted by rare disease.

LEGISLATIVE CONFERENCE

The Legislative Conference was a preparation day for going to Capitol Hill on Thursday. This annual conference is hosted by the Rare Disease Legislative Advocates (RDLA). The day long event provided an overview of the “asks” considered to be priorities for the rare disease patient community. The RDLA prepared legislative asks included:

- Support Creation of the Rare Disease Center of Excellence at the U.S. Food and Drug Administration (FDA)
- Enact the Newborn Screening Save Lives Reauthorization Act, H.R. 2507/S. 2158
- Support Increased Funding for the FDA Orphan Products Clinical Trial Grants Program and the Natural History Grants Program

In addition to learning more about each of these asks, deep-dive breakouts on the value of creating a Rare Disease Center of Excellence within the FDA and how patient-centered data can help improve access to treatments were also attended.

CAPITOL HILL DAY

On Thursday, Deb Van Zegeren joined over 800 Rare Disease Advocates on Capitol Hill to meet with members of Congress

SKINCARE
CORNER
Q&A

How can I best care for fissures on my palms and/or soles of my feet?

Fissures can be a difficult problem as they are painful and can make it difficult to use your hands normally or walk without discomfort.

Effective treatment of your CTCL will eventually help the fissures, but it can take months for treatment to work, or if medications or treatments lose efficacy, it can take time to find a new effective treatment.

To care for fissures, we want to protect the skin in these areas from other irritants, and also prevent infections from occurring. Wear gloves when doing any irritating or dirty work like washing dishes or cleaning.

In general, when washing your hands:

1. Hand sanitizers may be too painful to use, washing hands with a mild soap may be better
2. Use lukewarm water- Avoid HOT water.
3. Use a fragrance free mild soap. Most commercial hand soaps are harsh and contain fragrances. Some recommended products include:
 - Dove sensitive bar soap
 - Cetaphil gentle skin cleanser
 - CeraVe Hydrating Cleanser
 - Vanicream bar
4. Moisturize right after handwashing to “lock-in” moisture. You may need to use moisturizers several times a day, especially after hand washing. Some preferred moisturizers include:
 - Neutrogena Norwegian Formula hand cream
 - Cetaphil cream
 - CeraVe cream
 - Vanicream Moisturizing Skin Cream
 - Aveeno Eczema Therapy Cream
 - Petroleum jelly, Vanicream moisturizing ointment (formerly known as Vaniply), or Cerave Healing Ointment (may be too greasy feeling for daytime use)

For feet and hands:

1. Always apply your prescription medications (creams and ointments) first! Then apply your moisturizer. If possible, apply at different times of the day.
2. At bedtime, apply your prescription medication (if directed to do so) and an ointment like petroleum jelly, Vanicream moisturizing ointment, or Cerave Healing Ointment. Then cover your hands with cotton gloves or feet with cotton socks for the night.

Some patients find that applying a “liquid bandage” or another form of glue to fissures can help with discomfort. I recommend you discuss this with your dermatologist to get their opinion before you try this.

Keri Chaney, MD
Assistant Professor
Medical College of Wisconsin

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

CUTANEOUS LYMPHOMA PATIENT EDUCATIONAL OPPORTUNITIES

The Cutaneous Lymphoma Foundation is working to address the need for patient programs during this time of uncertainty. Our goal is to continue to provide educational and supportive content to our community through a virtual environment.

Please stay tuned for updates on our programs, including our 2020 2-Day Patient Educational Conference currently scheduled for June 27-28th. We look forward to continuing to serve your individual needs.

www.clfoundation.org/upcoming-events



Rare Disease Week...continued from pg 9

to make them aware of the impact of living with a rare disease. Deb traveled throughout the day with other delegates to see their Michigan state senators and representatives. As an advocate for the cutaneous lymphoma community, Deb shared that while our community is fortunate to have multiple treatments available, access to those treatments is a significant financial hardship for many and seriously impacts their quality of life. She also championed the proposed Rare Disease Center for Excellence as a way to improve the FDA’s approval process and continued funding for the National Institutes of Health (NIH).



RARE DISEASE DAY AT NIH

Laurel and Deb attended the Rare Disease Day at the National Institutes of Health (NIH) on Friday. The day began with a brief introduction and update of the different branches of the NIH related to rare diseases.

The first session focused on shortening the diagnosis process for rare diseases. There are 7000 recognized rare diseases globally – rare is defined as affecting less than 200,000 individuals. Within the United States, 25-30 million individuals are affected by rare disease. As we know from the cutaneous lymphoma community, many spend years searching for answers before receiving a diagnosis. Diagnosis remains a challenge, but advances in genomics, medical informatics and novel clinical approaches are helping to make progress toward quicker diagnoses.

The second session looked at precision medicine and individualized therapeutic approaches. The patient story of how researchers and clinicians developed a therapy for one child in order to give her a better chance of survival was inspiring. The lessons learned through this experience may help future researchers and clinicians in similar situations – especially when there are not enough individuals with the disease for a typical clinical trial protocol.

The final session introduced a nontraditional approach to improve access to specialized expertise. Project ECHO® (Extension for Community Healthcare Outcomes) is a telementoring program where less experienced providers are mentored by experts. The program offers much promise as a means to improve care for individuals who may not have direct access to a specialist.

To read the full summary of the Rare Disease Week events, visit our website: www.clfoundation.org/rare-disease-week-2020.



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TIME SENSITIVE MATERIALS ENCLOSED

*We are in this together...
navigating and adapting to these uncharted times...*



Thank you for trusting us throughout your journey with cutaneous lymphoma.

Your continued support has a tremendous impact on our ability to:

- Make a difference in the lives of those affected by cutaneous lymphoma;
- Provide quality information via programming and free publications;
- Provide assistance in identifying beneficial care and treatment options in response to email and phone inquiries.

As you are able, please support the Cutaneous Lymphoma Foundation by making a donation using the enclosed envelope or via our website:

www.clfoundation.org/giving-online