



Feeling Chained by the Invisible Enemy Named FATIGUE?



People in the modern world are tired, and that tiredness is often more intense for people living with cancer and other chronic illnesses. Fatigue can range from daytime drowsiness to feeling too exhausted to get out of bed.

Multiple factors contribute to fatigue; the most common causes include:

- poor sleep
- the severity of illness – sometimes called “disease burden”
- chemotherapy
- radiation therapy
- certain medications
- diet
- thyroid dysfunction

The Lymphoma Coalition, a non-profit network of lymphoma patient groups, conducts research to help lymphoma patients. Comprised of 83 member organizations in 52 countries, the Coalition’s vision is equity in lymphoma outcomes across borders. The Lymphoma Coalition’s 2018 survey identified fatigue as the leading physical symptom affecting quality of life.¹

According to their 2020 Global Survey, in which 470 CTCL patients participated, patients report fatigue as the second most common symptom, second only to skin changes. Of the 445 patients who answered the fatigue question, 244 (55%) indicated that fatigue has affected them.²

Fatigue is a long-term problem. Given CTCL’s chronic nature, patients in the survey describe fatigue lasting for eight years or more. 160 survey respondents said that they discussed their fatigue with their healthcare provider, and over one third said that the provider took no action.

The Cutaneous Lymphoma Foundation (CL Foundation) defines fatigue as a decreased capacity for activity, often accompanied by feelings of weariness, sleepiness, or irritability. The CL Foundation’s patient handbook, “A Patient’s Guide to Understanding Cutaneous Lymphoma,” suggests anticipating fatigue and pacing yourself, building rest periods into your day as needed, and adjusting your work schedule wherever possible. Historically, this has been the common advice given to cancer survivors, regardless of diagnosis.

However, according to the American Association for Cancer Research, evidence continues to mount that cancer survivors who engage in exercise experience numerous physical and mental health benefits including increased activity tolerance, improved quality of life, and decreased depression and anxiety.³

In 2010, the American College of Sports Medicine (ACSM) Roundtable concluded that cancer survivors could safely engage in enough exercise training to improve physical fitness and

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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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FROM THE BOARD PRESIDENT

Hello to All,

In April of 2013, a very special meeting was held in northern Virginia. Seventeen people responded to an invitation from the Cutaneous Lymphoma Foundation to meet and explore the possibility of forming a DC area patient networking group. For years I had dreamed of being part of such a group, and fortunately the CL Foundation was committed to making it a reality. Eight years and many meetings later, I don't know how many individuals have attended a CL Foundation DC patient networking group event, but I do know that they shared the common need to meet and connect with others who would understand their disease and the impact that it had on their lives.

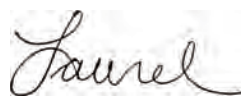
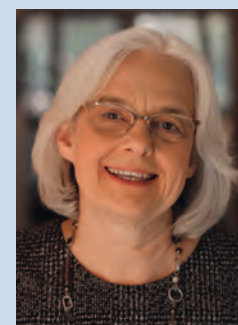
Unfortunately, the pandemic has made our ability to meet and interact with others a challenge. We have not had an in-person patient educational event in over a year, and the CL Foundation DC patient networking group, which would normally meet several times each year, has not met in-person since January of 2020. However, we have not been idle, and as in-person programs have been replaced with webinars and Facebook Live events, our meetings were also converted to an online format. We soon realized that this new version had literally opened up a world of possibilities. Location no longer limited one's ability to attend. Now, anyone, anywhere in the world who would like to meet and participate in a discussion with others in the cutaneous lymphoma community, only needs a smart device to do so. Since initiating online patient networking group meetings on the first Tuesday of each month, registrants have participated from all areas of the US,

as well as other countries. Our ability to offer this opportunity to everyone is certainly on the list of good things that are a result of the pandemic.

Our need to connect, in person or virtually, is a strong one for many people with our disease. One only has to attend one of these online meetings, read the postings on patients' Facebook pages, or join the Foundation's Community Connections group to see many examples. People want to know about medical resources, treatments, and most importantly, is there anyone else who is going through what they are. One could say that we don't heal in isolation, but in community.

I want to recognize and thank everyone who helps to provide a community for our patients and their families. Our staff, Susan, Holly, Deb, Sue, and Hilary are amazing. The Facebook responders who are there to provide empathy and advice are also amazing. And most amazing to me, are the members of the CL Foundation DC group who have provided endless support for one another for eight years and are now sharing their experiences with our global community.

I hope you all are safe and well and that each of you has found your community.

Laurel Carlson

FROM THE CHIEF EXECUTIVE OFFICER

Welcome Spring 2021!

Worldwide, we can look in the rearview mirror and marvel at the change we have all experienced in a short time. COVID-19 has impacted all of us, some more directly than others, but everyone has been touched in some way. What are you looking forward to post COVID? We'd love to hear about your dreams and wishes. Let's begin to look forward once again.

Today we have vaccines in various waves of availability depending upon the country you live in.



Susan Thornton

From the CEO...continued on page 11

Living with Cutaneous Lymphoma, Patient Update

Brett Weiss

It's been almost seven years since the day I was diagnosed with mycosis fungoides. It's remarkable when thinking about how much change has happened in that time. Since the video of my story hit the Cutaneous Lymphoma Foundation's website, I have had the privilege of being able to speak to so many individuals recently diagnosed with this condition. It has been one of the most rewarding experiences to be able to help others who are just starting their journey living with this condition. One of the most consistent things I hear from these people is how nice it was to see that I am able to go on with my life as I monitor the disease over time.

When the Cutaneous Lymphoma Foundation asked me to update all of you on where I am now, I was honored and so happy to be able to share details on the last few years. With all the change 2020 has brought the world, it has also brought identical twins into our family. In February 2020, in Manhattan, New York, my incredible wife Emily gave birth to our identical twins Summer & Brooklyn. Less than a month after their birth, COVID-19 hit the world and everything changed for everyone. I continued to work in direct patient care as a physical therapist in New York City with a large focus on treating the jaw (and yes...in treating inside mouths during COVID-19 was a bit terrifying with newborns at home).

In August 2020, my wife Emily, our three-year-old dog Oakley, and our twins moved across a closed border to Toronto, Canada. It was a stressful experience; however, once we arrived we found calmness, and immediately appreciated the increased living space of a townhome versus our one-bedroom NYC apartment. While we miss the lifestyle and convenience of New York City, we have been enjoying the open air, ease of getting in your car to get groceries, and the free healthcare is a great plus!

Watching the girls learn to roll, crawl, and now walk has been a true blessing. Looking back a few years ago, I would have never thought I'd be a father by age 33, let alone to two children! They are identical but so different in so many ways. It's fascinating to see how two nearly genetically identical people, growing up under the same circumstances, can be so wildly different in personality.



In 2020, I also started my business ErgoSesh, a virtual ergonomic consultation company focused on educating and empowering the workforce to take wellness into their own hands. We do this by thoroughly educating employees about ergonomic best practices and injury prevention in a one-on-one, laid-back conversational setting. In addition to this, we are a full-service supplier of high-quality ergonomic furniture. We work with many companies who understand the importance of investing in their employees' wellness at the point of onboarding to the company. My vision for the future is that more and more employers onboard their people with this type of experience from the start, sending a clear message to each employee that maintaining their physical health is a priority to the company.

With the shift to digital everything, along came the shift to digital conferences. We noticed that more and more companies were holding 24-to-36-hour online conferences once the pandemic hit. Expecting people to sit at their computers for hours at a conference is a lot to ask, and we have the solution to keeping people engaged while giving them a physical and mental break.

During the 2021 Cutaneous Lymphoma Foundation Virtual 2-Day Conference, ErgoSesh will be unveiling ErgoBreak, a series of educational, movement and meditation breaks to help you unwind, stretch, and provide you ergonomic tips and tricks to help you manage this shift to working remotely. We believe you'll love the breaks and hope you'll use the information for years to come!

See you all at the conference!

Brett Weiss, DPT, CEAS, Co-Founder & CEO

ErgoSesh

COVID-19 Frequently Asked Questions

The following COVID-19-related questions were addressed by **Jasmine Zain, MD, City of Hope National Medical Center** and **Lucia Seminario-Vidal, MD, Moffitt Cancer Center**. Please consult your own doctor with any specific questions.

1. If I have cutaneous lymphoma, should I get the COVID-19 vaccine?

Vaccination is an important consideration for adults of any age with certain underlying medical conditions, including cancer, because they are at increased risk for severe illness from COVID-19.

Immunization is recommended for all patients receiving active therapy, with the understanding that there are limited safety and efficacy data in these patients. There are a few exceptions. Please discuss with your doctor.

If you are receiving certain chemotherapy agents or a cellular engineered therapy, your vaccination may need to be delayed in order to maximize efficacy. Please discuss with your doctor.

If you have received a stem cell transplant, then your vaccination may need to be delayed until three months have passed after your transplant.

NCCN: Cancer and COVID-19 Vaccination version 1.0 1/22/2021;
<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html>

2. Will I have side effects from the vaccine?

Some people may develop side effects which are normal signs that your body is building protection. The most common side effects are pain and swelling in the arm where you received the shot. In addition, you may have fever, chills, tiredness, and headache. These side effects may affect your ability to do daily activities, but they should go away in a few days.

Side effects are more common after the second dose (Pfizer and Moderna vaccines). You may take Tylenol or other similar medications if side effects are moderate to severe.

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html>
 (Accessed 02/21/21)

3. What are the guidelines with the vaccine as it relates to stem cell transplant?

Vaccination should be delayed for at least three months following HCT. You should always consult with your transplant physician before receiving the vaccine.

NCCN: Cancer and COVID-19 Vaccination version 1.0 1/22/2021

4. Can I get the vaccine if I am receiving CAR-T therapy? Campath? Additional treatments?

CAR-T: It is recommended that vaccinations be delayed for three months after CAR-T cell therapy. If this treatment is planned for you, then it may be possible to receive the vaccine prior to getting the CAR-T therapy. Please discuss with your physician.

Campath: There is very limited data, but based on the mechanism of action of this agent, it is unclear if the vaccine will have any efficacy in patients who are currently receiving Campath. Most physicians will recommend waiting for three to six months after completing therapy with Campath before receiving the vaccine. If possible, treatment should be delayed until after the vaccination is completed.

Multiple Sclerosis and SARS-CoV-2 Vaccination: Considerations for Immune-Depleting Therapies Johann Sellner 1,2,3,* and Paulus S. Rommer 4

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COVID-19 Frequently Asked Questions

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5. If I am fully vaccinated, do I still have to wear a mask and practice social distancing?

Even if vaccinated, you and your close contacts should continue to wear masks, stay at least six feet away from others, avoid poorly ventilated spaces, avoid crowds, wash hands frequently, and follow other recommendations for COVID-19 prevention.

It is not yet known whether getting a COVID-19 vaccine will prevent you from spreading the virus that causes COVID-19 to other people, even if you don't get sick yourself.

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html>
(Accessed 02/21/21)

6. If I have cutaneous lymphoma, will my immune response to the vaccine be weaker?

Patients with cutaneous lymphoma were not included in the clinical trials of vaccines, so a definitive answer is not known. The current recommendation is that everyone who can get a vaccine should be vaccinated with few exceptions that have been discussed above (stem cell transplant, CAR-T therapy, and few anticancer therapies). Any protection is better than no protection.

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html>

7. Is there anything in particular patients with cutaneous lymphoma should be aware of as it relates to the vaccine?

Make sure to have a discussion about the vaccine with your doctor. Any side effects from the vaccine should be reported as well. Follow the guidelines from CDC and other health agencies.

8. I have heard that immunosuppressive therapy may be beneficial if you get COVID because your body won't overreact to the disease, is this true?

This is not true. The immune response to SARS-CoV-2 is complicated and involves many aspects of the immune system. Patients who are immunosuppressed may not be able to mount a response to the virus and it may spread more rapidly causing a more severe illness. In addition, it may take longer for the virus to be cleared by the body if the immune response is poor.

Immune Determinant of COVID 19 disease presentation and severity: Peter Brodin Nature Medicine ; 27 28-33 (20210

9. Are people with indolent cutaneous lymphoma considered higher priority to receive the COVID vaccine?

According to CDC guidelines, patients with cancer, including cutaneous lymphoma, are part of priority group 1b/c, which means they should be immunized when vaccination is available to them.

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines>

10. If I am vaccinated but my family/friends are not, can I be around them safely?

You can continue to be around family members that you live with in accordance with the safety guidelines by the CDC. You need to continue maintaining social distancing for members outside your household which includes masking, hand washing and maintaining at least a six-foot distance. Depending on the rates of transmission in your community, your local health authorities issue guidelines about social gatherings that you need follow until the pandemic is over. 🌐

Frequently Asked Questions

Has cutaneous lymphoma research come a long way in recent years?

Dr. Jasmine Zain: Yes, absolutely. Cutaneous lymphomas are rare, that's why we don't hear much about it. Compared to breast cancer or lung cancer, the incidence and prevalence is much lower, but it is also a disease where there's an unmet need we call it, because there are a lot of patients who live with this disease, so we want to help them, and we want to make sure they have good quality of life. There is a lot of research going on and from a scientific perspective, it's an easy disease to study because we can do lots of skin biopsies and we can really apply that knowledge we learn from understanding the tumor environment to other cancers as well – mechanisms of actions and figuring out which drugs work. There's a lot of work being done in this field.

What is the best over-the-counter and prescribed cream for itch?

Dr. Jasmine Zain: The dermatologists that I work with in the cutaneous lymphoma clinics recommend Cerave if you have very dry skin, especially if you're undergoing treatments like light therapy and things like that, it's very useful to use it in areas of very dry skin; it is very thick to apply.

In terms of prescribed medications, we use a lot of steroid-based creams to help with the itching, they come in different strengths. For areas of your face, you could use hydrocortisone, that's over-the-counter. And then for more extensive areas we sometimes recommend a stronger steroid. Triamcinolone is my favorite, it's 0.1%, it's prescribed, and you can get a whole jar of it so that's my recommendation.

Dr. Bradley Haverkos: More difficult spots to treat we might use a stronger steroid like Clobetasol, that's

the one we tend to use a little bit more sparingly and not apply it for long durations of time to sensitive areas of skin or like the face where it's thin because sometimes you can have long-term issues with the stronger topical steroids. Other things to add would be some of the topical chemo drugs like Valchlor, sometimes we use topical retinoids, those are prescribed topicals, but are useful a lot of times as an adjunct to some other therapy, but they are good options especially for early-stage cutaneous lymphoma. 🌐



Answers provided by:

Brad Haverkos, MD, MPH, MS
Anschutz Cancer Pavilion

Jasmine Zain, MD
City of Hope National Medical Center

Questions and responses taken from our
Answers from the Experts LIVE video recording from
November of 2020. For the full-length video, please visit:
https://www.youtube.com/watch?v=TbMAk9F_q48&feature=youtu.be

Life after COVID

We are all looking forward to returning to doing the things we love the most and have missed due to COVID-19. We asked what YOU are looking forward to the most, and we hope that reading these make you smile. We are all in this together, know that you are never alone!

Returning to Tuesday night pottery! • *Seeing my Dallas grandchildren whenever I want, travel, and social gatherings. Basically, I'm looking forward to life the way it was before Covid.* • **See and hug my family. And meet my nephew who was born last May!** • Spending the weekend with my family at the beach! • **Hosting a family party and hugging my parents! Resuming travel!** • **I'm looking forward to going out to dinner and hugging my beautiful granddaughter. I'm really getting tired of my cooking!!** • Attending church in person; sharing holidays, birthdays, & special events with family & friends; traveling abroad for the first time. • **Doing more activities outdoors.** • Seeing my Mom. She is in a nursing home in another state. • **Vacationing in the mountains with my family.** • *Shopping and dining with friends.* • **Going to church with neighbors.** • Maybe taking a trip to sunny Florida :-) • **Seeing my son, who lives out of state** • *Seeing people's smiling faces without masks and hugging (I'm a hugger)!* • Doing the same thing over and over every day as a retiree it feels like "Groundhog Day". I will be happy to get out more and to visit my family and friends that I haven't seen. • **Resuming annual visits to Europe visiting Family.** • Hugging and kissing my grandchildren! • **Meeting up with and hugging my two grown-up sons!** • **Seeing my grandchildren.** • Travel, see friends, eventually giving up the mask, and hugging my grandchildren. • *Getting together with friends, doing lots of travel, and going to Florida for the winter. Seeing my friends again and giving them THE BIGGEST hug!!* • Rescheduling the trip to Israel and Jordan that was cancelled this past November. Also traveling up north and seeing my grandchildren. • **Seeing and hugging my grandchildren. It's been a very lonely year.** • *Hugging my friends for as long as I want! Strolling in and of stores without rushing or keeping social distance.* • **Attending movies, theater, concerts and museums again.** • Eating indoors at my favorite restaurants without fear. • **Having dinner with friends.** • **Visiting and hugging my family and friends!!!**



• We have cancelled 3 cruises. We now have one scheduled for December and hope we can go. • **Returning as much as possible to the life I had before – walking to as many places as possible, and attending various cultural events, sometimes at the spur of the moment.** • Miss being social with my friends and going to restaurants, concerts, sports events and theaters. Gosh how I really miss going to a movie theater. • **Being able to talk face to face.** • Hugging people. Getting a professional haircut. Traveling. • **Going skiing with my kids!** • **Visiting my mother whom I have not hugged since 2009.** • **Travel.** • I would like to invite my families over my house for a happy gathering celebrating the end of Covid-19! Next I would invite my friends to gather and celebrate with me! • **Hugging somebody.....anybody! :-)** • **See family and friends in person.** • Resuming weekly Sunday visits with my two grandsons, ages 3 and 16 months. After dinner, we would play silly games until we were all exhausted. We had lots of fun and I truly miss that time with them. • **In the future I am looking for to seeing my family and friends and not be feeling like I'm alone.** • Traveling to different places with my friends. I really miss being able to go on a vacation. • **Seeing my family and friends.** • Being able to participate in person with my church family. • **Going on a girls' shopping weekend with family and friends!** • Flying to the west coast to visit my brother. • **Visiting and hugging all of my grandchildren! I am also looking forward to going out to a restaurant with my friends.** • **It'll be nice for hearing impaired folks, like myself, to be able to understand what people are saying once we can get rid of these damned masks.** • I think surviving and fighting NHL prepared me to do battle against catching Covid -19. That being said While of course I will be glad to live normally again. There will have to be a reintegration period. Like just going to a get together with friends, mentally I will have to accept it will be fine and not worry. • **Spending time with family and friends – inside and without masks!!** • I look forward to finally seeing my new great grandchild. She is 11 months old now. I missed her birth and the first eleven months of her life. I haven't seen my daughter or grandchildren in over a year. I get my second vaccine soon. I will be able to

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Feeling Chained by the Invisible Enemy named FATIGUE? *continued from pg 1*

reduce fatigue.⁴ Their second Roundtable in 2018 concluded that every cancer survivor should “avoid inactivity” and that engaging in moderate-intensity aerobic training three times per week can significantly reduce cancer-related fatigue, both during and after treatment. The ACSM encourages cancer healthcare providers to “Assess, Advise, and Refer” and strives to connect cancer survivors to the most appropriate exercise programming. Find the programming registry at www.exerciseismedicine.org/movethruca

During a recent CL Foundation Facebook Live event⁵, Dr. Farrah Abdulla, Professor of Dermatology and Dermatopathology at City of Hope in California, said that patients with patch disease are not “expected” to have fatigue as a complication. Patients with more advanced disease, however, may more commonly feel fatigued. “It really depends on the stage of the disease and the extent of involvement”.

Dr. Abdulla also discussed how drugs, such as oral bexarotene (Targretin), depress the thyroid, which can cause fatigue. It is important to monitor blood tests, specifically the free thyroxine level so that patients can be “boosted with synthetic thyroid hormone to keep energy levels up.” Dr. Abdulla also noted that coexisting medical conditions may contribute to fatigue.

Susan Thornton, the Cutaneous Lymphoma Foundation Chief Executive Officer and a CTCL patient herself, describes how poor sleep and life stresses, possibly unrelated to CTCL, contribute to fatigue. Susan encourages ongoing discussions with your healthcare provider to determine if fatigue is “disease-related, or lifestyle-related”. Susan describes both an emotional and physical fatigue from long-term treatment.

Unsurprisingly, research data validates Susan Thornton’s opinion on fatigue. The Journal of Psychosomatic Research suggests that up to 45% of ALL American adults are chronically fatigued.⁶ It’s an interesting thought to consider that you may feel fatigued, completely independent of your CTCL diagnosis.

Dr. Basem William, former Director of the T-Cell Lymphoma Program at Ohio State University, discussed fatigue at another CL Foundation Facebook Live Event⁷ in late 2019. Dr. William also encourages patients to discuss fatigue with their doctor. He, too, describes mental and emotional fatigue in CTCL patients and emphasizes the need to rule out organic causes of fatigue.

“We are complicated creatures,” says Dr. William. “Our mind affects how our body functions, so exercise certainly

reduces stress. Exercise releases a lot of substances inside the brain naturally. It’s the same substance that drugs like morphine release, giving a sense of relief of pain. It gives a sense of pleasure, a relief of tension. This can be obtained naturally and in a healthy way by trying to adhere to a low-intensity exercise program.” He also notes the importance of a healthy diet.

Dr. William believes that his patients face another struggle; the isolation that comes with a rare disease. He states that “connecting with people that have similar struggles to yours can be very uplifting.”

Dr. William states that, ironically, “Exercise works better if you are tired. Committing to a low-intensity exercise program can have a tremendous, positive impact on quality of life.”

However, recent studies show that low-intensity workouts, although likely to have other benefits, are unlikely to reduce fatigue. Moderate-intensity aerobic training three times per week can significantly reduce cancer-related fatigue, both during and after treatment.

If you participate in a low-intensity exercise program and are still feeling fatigued, talk to your doctor about kicking it up a notch. Ask your doctor about the Exercise is Medicine program and get your customized prescription for exercise.

Are you starting a workout routine? Do you need a battle hymn? Try the song by the 1970’s Canadian punk rock band, The Diodes, titled “Tired of Waking Up Tired”: <https://www.youtube.com/watch?v=9eyBzgnvDF4>

Maybe this song will become the anthem of the Cutaneous Lymphoma Foundation and cancer survivors everywhere.

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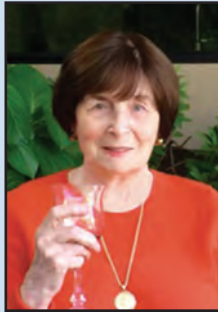
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In Memoriam and Honor of Terri Bracken Schruben

The Cutaneous Lymphoma Foundation mourns the passing of Terri Bracken Schruben, a generous benefactor to the Foundation. Terri tragically died from injuries sustained in a car accident only five minutes from her home.

Terri was born in Dublin, Ireland, and trained as a nurse in England. After working for a number of years in Dublin, she moved to work in Toronto. During that period, she vacationed in San Francisco, fell in love with the city and ended up working at St. Mary's Hospital for a number of years before moving south to St. Vincent's Hospital in Los Angeles. During her tenure in LA, she took leaves of absence to work in the Harley Street Clinic in London and the American Hospital in Paris. When she retired, she was the head nurse in the cardiac and transplant unit at St. Vincent's. Terri met her future husband while living in LA, and after they were married, they moved to beautiful Carmel, California. While living in Carmel, Terri served as a volunteer for hospice.

Terri was diagnosed with cutaneous lymphoma in 1995 and managed it well using a variety of therapies including nitrogen



mustard. Terri's doctor told her about the Foundation, and she was delighted to learn of all the resources the Foundation offered. Terri was so grateful for the assistance, support and knowledge she received from the Foundation, that she generously provided a \$50,000 gift to the Foundation in her estate plan. Terri's generous donation will be used to support research into the causes of and treatment for cutaneous lymphoma, and to enhance and support patient education. We hope it will also serve as an example to inspire others to support the Foundation. As someone working in the medical field, Terri realized the importance of medical research, and as a patient, Terri appreciated the invaluable support and information she received from the Foundation.

This extraordinary gift from Terri will provide much needed funds to help the Foundation realize its goal of a world without cutaneous lymphoma.

On behalf of the Cutaneous Lymphoma Foundation, we extend our deepest sympathies to her family and friends, and are extremely appreciative of Terri's support.

Feeling Chained by the Invisible Enemy named FATIGUE? *continued from pg 9*

4 Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, Zucker DS, Matthews CE, Ligibel JA, Gerber LH, Morris GS, Patel AV, Hue TF, Perna FM, Schmitz KH. Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable. *Med Sci Sports Exerc.* 2019 Nov;51(11):2375-2390. doi: 10.1249/MSS.0000000000002116. PMID: 31626055.

5 Cutaneous Lymphoma Foundation, Facebook Live: Open Q&A with Dr. Farah Abdulla, February 2020. https://youtu.be/pp1NKERPZ_M

6 Doerte U, Junghaenel, Christopher Christodoulou, Jin-Shei Lai, Arthur A. Stone, Demographic correlates of fatigue in the US general population: Results from the patient-reported outcomes measurement information system (PROMIS) initiative, *Journal of Psychosomatic Research*, Volume 71, Issue 3, 2011, Pages 117-123, ISSN 0022-3999, <https://doi.org/10.1016/j.jpsychores.2011.04.007>. (<https://www.sciencedirect.com/science/article/pii/S0022399911001401>)

7 Cutaneous Lymphoma Foundation, Facebook Live: Clinical Trials with Dr. Basem William, September 2019. <https://youtu.be/K99-pocUh9I>



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From the CEO...continued from pg 3

That's a significant relief for many of us knowing that we could be in the final stages of living day-to-day in the shadow of COVID-19. We've done our best here at the Foundation to stay on top of the information as it becomes available. In addition to the COVID-specific page on the website, we have convened a clinical COVID taskforce to create a FAQ to help guide you as you make your personal decisions around the vaccines. The updated guide is featured in this edition. There is so much we don't know yet, especially related to cutaneous lymphoma. As more information becomes available, we will post it.

A few months ago, we had dreams of hosting our annual 2-day Patient Conference in person this year. That was probably a bit too optimistic. However, we are excited to host the program virtually this June. As you may have noticed, our virtual programs have expanded exponentially this year. Please check them out and plan to join us for one or all of them. The monthly virtual networking groups have also been growing. If you are looking to connect with others, set aside the first Tuesday of the month to jump into the group or become a Community Connections member to join the online community message boards. There are many ways to become engaged – choose the ones that fit your interests and needs and let us know what's missing. Our goal is to offer what you find most valuable.

By now, you should have received your copy of the new Research Roadmap outlining our big, audacious goals for building a long-term, sustainable research grant funding program. If you missed our March webinar

with three Research Advisory Council members, check it out on our website: <https://www.cffoundation.org/research-award-program>. It's exciting to begin this next chapter in the Foundation's commitment to research support. As the patient community, we can do so much to help add to the scientific knowledge and change the future for everyone living with this rare skin lymphoma. I invite you to join us in making progress toward our \$1 million research goal.

Our world has changed in the last year, and the Foundation has changed along with it. Thank you to everyone who has continued to support our mission in these challenging times. As I've said before, we can't do our work without you.

I leave you with this quote:

“We are each of us angels with only one wing and we can only fly by embracing each other.”

– Luciano de Crescenzo

We are all angels traveling together through a difficult journey. Collectively we support each other so each of us can make our unique contribution. The Foundation is here to serve you in whatever way you find most valuable.

Take good care and be well – see you down the road!



Life after COVID...continued from pg 8

see them in April. My daughter got COVID. I will finally get to hug her soon. • **I am looking forward to again see people in 3 dimensions.** • *I am looking forward to getting more updated information on the treatment of the Sezary syndrome.* • Being free to come and go as I please once again without the fear of getting infected with a possibly deadly disease! Can't wait for my husband and I to go out for dinner! Also -- haven't have a haircut in a year! • **Traveling to visit my son and daughter who live out of state.** • Following the Covid Pandemic, I am most looking forward to having a “Birthday for All Party” with my family of wife, six children, and six grandchildren (ages 0 to 6 years old), since we missed an entire year of Birthday Parties so far... • **Visit my sister in UK** • **Being able to visit**

my step-sister in VA, and my Step-Mother in FLA, both of which are quite ill. • *Take my children for a long trip.* • **Spending time with family and friends.** • **Seeing live entertainment again!** • I am most looking forward to getting together with my friends and family. It has been over a year since we were able to get together. I really miss everyone. I haven't been to any stores since March 2020. I can't wait to go to my favorite stores. Costco, Lowe's and Home Depot. • **Going to the movies again and sharing popcorn with a friend.** • **Hugging my grandchildren.. a lot!** • **Traveling with family and friends!** • *Being able to be out in the community more with greatly reduced chance of becoming ill with Covid-19. I am very excited to be getting my first vaccine in a few days!* 🍀

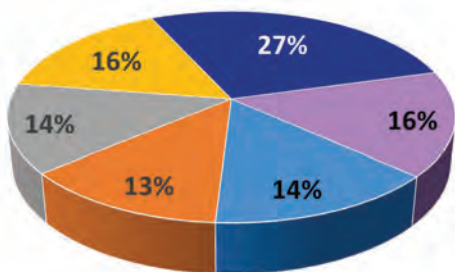


CUTANEOUS LYMPHOMA FOUNDATION
PO BOX 374
BIRMINGHAM, MI 48012

TIME SENSITIVE MATERIALS ENCLOSED

Making The Most of Every Dollar You Donate

**Your 2020 Donations -
Making a Difference across
Cutaneous Lymphomas**



- Educational Events
- Advocacy & Awareness
- Patient & Caregiver Support
- Educational Information/Publications
- Research
- Administration and Fundraising

Did you know, a gift of:

- \$25 – will send educational literature to someone seeking much needed information
- \$150 – will ensure someone needing one-to-one support gets it
- \$500 – will provide people worldwide access to online events and resources
- \$1,500 – will provide a Young Investigator Award to a researcher early in their career
- More than \$1,500 – will promote awareness, provide education, advance patient care, and foster research!

Every dollar you donate, is equally important in eliminating the burden of cutaneous lymphoma.

MAKE A DONATION TODAY!

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