



QUALITY OF LIFE: REVISITED PART 2¹

Quality of Life (QoL) issues affecting people with cutaneous lymphoma (CL) have become an ever-increasing part of the conversation between patients, care partners, and health care providers. To date, research efforts around the globe indicate an increased interest and awareness of the need to pay attention to the QoL of CL patients and to provide increased resources for both patients and providers to keep QoL in the forefront of the care and treatment of patients with CL. One such resource, the MF/SS-CTCL QoL instrument, is presented here in Part 2 along with other relevant research findings based upon a methodical, wide-ranging review of the literature on the topic of QoL.

Further adding to the knowledge base on QoL for people affected with CL, this article explores another important study done as a collaborative project. Using a patient-centered approach, the first CTCL-specific, 12-item QoL tool has been developed through both qualitative and quantitative methods, meeting the project’s objective of developing and validating the first specific MF/SS-CTCL QoL tool.^{2,5} Review of the literature complemented patient interviews of those self-reporting a diagnosis of mycosis fungoides or Sézary syndrome; the resulting information gleaned was used to develop a framework for the item-development. Additionally, input from experts and key opinion leaders in CL went into the development process.⁵ Following a questionnaire refinement process that involved further patient interviews and debriefing surveys, a preliminary MF/SS-CTCL QoL tool was developed and tested.



Through collaboration with the PatientsLikeMe Open Research Exchange (ORE) and the Cutaneous Lymphoma Foundation, 126 participants completed both the preliminary MF/SS-CTCL QoL instrument, and the widely employed and previously validated SkinDex-29 instrument, currently in routine use to assess QoL in patients with skin diseases, including CTCL. Following this, participants were asked to take the MF/SS-CTCL QoL questionnaire again to check for test-retest reliability. Of the original 129, 66 participants completed the tool a second time. In order to ensure the strength of the questionnaire, multiple psychometric measures were then used to finalize the final 12-item instrument which withstood the extensive testing for validity and reliability, measurement precision, and person-to-item targeting, among others.⁵ The items include MF/SS-associated concepts dealing with illness-re-

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2023 Issue 2 - Education & Support Services Edition

Ensure that everyone with cutaneous lymphoma and their care partners are empowered to be involved in their care and live well with their condition.

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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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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 in part thanks to the following generous supporters:



FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO



This is the era of “we”.

It takes courage to show up at an educational program or networking group meeting. Whether in person or virtually, those of you who are brave enough to participate make the work of the Foundation worthwhile.

The opportunity to meet in person again at our 2-Day Conference in Bethesda was magical. I'm unsure if it was because this was the first time we'd gathered on multiple days since 2019, if the agenda provided more time for connecting, or if it was the patient panels or clinical speakers. Perhaps a combination of all those things. There is something special about the energy you can feel when gathered together. Read more about this year's 2-Day on pages 6-7 and check out the presentations on our YouTube channel.

Grappling with the lessons learned during the pandemic, it has become apparent that this community of individuals, whether diagnosed with a form of cutaneous lymphoma or someone who loves them, is at the core of the Foundation. Of course, bringing up-to-date education and information to your fingertips is one of the cornerstones of our work, yet without you, our beloved community, we can't have the impact we strive for to alleviate the burden of cutaneous lymphoma worldwide.

To do that, we need YOU! Your participation, your insights, your ideas, and your willingness to be a champion for yourself and others who may be challenged as they deal with navigating this disease journey.

There are many ways for you to become engaged. Reading this Forum is a good start! Join us for the monthly networking group meeting and share your experience with others. Come to one of our upcoming in-person patient educational forums. Join the private, online Community Connections. If you can, provide financial support to help us invest in our capacity to deliver our programs and services globally. Or host a fundraising/awareness event in your town.

As Coretta Scott King said,

“The greatness of a community is most accurately measured by the compassionate actions of its members.”

Thank you for being an active part of our community. Share what you have learned with others. Help us change the world one person at a time.

Until we meet again - be brave, be bold, and let us know how we can continue serving you.

Laurel Susan

A TRULY MIRACULOUS OUTCOME

Shared by Barbara B.

In 2017, I wrote an article for the Cutaneous Lymphoma Foundation's Forum newsletter about my husband, Victor, and his 25+ year CTCL/mycosis fungoides (MF) journey. It detailed the outstanding improvement to his mycosis fungoides that occurred when we searched out a team of specialists at our treatment center in Palo Alto, California.

Twenty-five years of various treatments, including PUVA, oral bexarotene, topical nitrogen mustard, chemo (romidepsin, liposomal doxorubicin, brentuximab vedotin) and TSEBT (Total Skin Electron Beam Therapy) low-dose radiation, allowed my 7' tall, ex-NBA pro basketball player husband to attain varying levels of control over his MF for periods of time. We thought that fully eradicating the CTCL/MF wasn't a solution that would ever be possible in our lifetime.

We are excited to announce that Victor is now being classified as in REMISSION! This is truly a miraculous outcome after his decades of struggles with CTCL/MF and we hope this article inspires the Forum's readers to understand that great leaps forward are being made via cutting-edge research.

Victor participate in a CRISPR CAR-T Clinical Study using gene-editing to try to modify stem cells to eradicate his CTCL/MF. When the process was explained to Victor, he thought it sounded like something from a science fiction movie but he readily agreed to be one of 18 patients included in the study, which was administered in multiple medical centers in the U.S.



Barbara and Victor

Just prior to the infusion of the CAR-T gene-edited donor stem cells on September 9, 2021, a blood sample was taken and it indicated that Victor had over 1600 CTCL/MF cells present in the blood sample. After that blood sample was taken, the CAR-T gene-edited donor stem cells were easily injected through a picc line that had been placed in his upper arm. No side effects ever developed. Fourteen days later, another blood test revealed ZERO CTCL/MF cells detected. Subsequent blood samples, over the past eighteen months, continue to show that the CTCL/MF is no longer present in Victor's blood.

A couple of very small spots of CTCL/MF did develop on Victor's skin in the first six months after the infusion of the CAR-T gene-edited donor stem cells, all of which were easily neutralized with a couple of spot treatments of TSEBT. We were informed that the spots were the result of some leftover CTCL/MF cells that had already invaded the skin layers prior to the CAR-T infusion. His doctors recently advised us that Victor is now considered to be in remission, and they will continue to routinely see him and follow his lab results every three months for another 3.5 years of the CRISPR CAR-T Clinical Study 5-year term.

With the treatment center located a distance of three hundred miles from our home, participation in the clinical study was made infinitely easier by Angel Flight West's scheduling of private pilots and their aircraft who volunteered to fly us from



Jennifer Doudna and Emmanuelle Charpentier, at UC Berkeley, were awarded Nobel prizes in 2020 for their discovery of gene-editing, a genetic manipulation in which a living organism's genomic DNA is deleted, inserted, replaced, or modified, and it was first studied in the early 1900s. Through a major gene-editing technique called CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats), the treatment and eradication of diseases through directly modifying the patient's disease-related DNA has been proven successful.

In 2021, the lead oncologists in our incredible oncology team at our treatment center, approached us with the idea of having

our city to the treatment center city for all of Victor's appointments and labs, for free. There are multiple Angel Flight nonprofit organizations across the U.S. and more information can be found at www.angelflight.com.

DON'T MISS OUT...

Upcoming Events to Watch For

International Patient Conference - Virtual
Saturday, September 9, 2023

Patient Educational Forum
Denver, Colorado
November 2023

Visit

www.clfoundation.org/upcoming-events
or scan the QR-code below
to more learn about upcoming events.



Stay Up-To-Date With The Cutaneous Lymphoma Foundation

Subscribe to the Foundation's YouTube channel (CutaneousLymphomaFnd) and follow us on Facebook and LinkedIn.



Blood Cancer Month - World Lymphoma Awareness Day - Rare Cancer Day

People affected by cutaneous lymphomas need your help!

With awareness events throughout September such as Blood Cancer Month, World Lymphoma Awareness Day, and Rare Cancer Day, we couldn't pass up the opportunity to focus the world's attention on the needs of the cutaneous lymphoma community!

With your help, we've dedicated September to **cutaneous lymphoma awareness**. Come join us and be a **champion** for all people affected by this rare group of cancers.

Follow, Like and Share via social media and contact us today to learn more about how to become a **champion** for the cutaneous lymphoma community.

Email us at volunteers@clfoundation.org or use the QR code.



We are so incredibly grateful for our treatment center team of wonderfully caring, supportive, and top-level oncologists and how they collaborate with the incredibly dedicated and successful research teams at CRISPR Therapeutics, as well as for the multitude of kind and friendly Angel Flight pilots who transported us. This whole group made it possible and quite easy for Victor to massively benefit from the CRISPR CAR-T Clinical Study. Together, they've given Victor the ultimate gift of a cancer-free life and our family sends out a huge thank you to all! ❖

We suggest you search out medical teams that are actively aware of, and participating in, new clinical studies that could possibly change the outcome of your CTCL journey. In addition to asking your doctor, online resources such as ClinicalTrials.gov, cancer.gov/about-cancer/treatment/clinical-trials and the Cutaneous Lymphoma Foundation's website can help you find current cutaneous lymphoma clinical trials.

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"This conference opened my eyes to so much information, research, skin care, just meeting other people just like myself was amazing. Everyone was so kind, so friendly, ready and willing with any questions you have, simply amazing." – Conference Attendee



After three years of meeting virtually, it was great to be together again in person for this year's 2-Day Patient Conference in Bethesda, Maryland. Nothing compares to being face-to-face.

Conference sessions held in the auditorium were streamed to offer a virtual option for those who could not attend in person (recordings available at <https://bit.ly/2DayPlaylist>). We were pleased to be able to provide a quality experience for those who joined us online.



Together Again!



We were excited to be joined by many clinicians who are experts in the field of cutaneous lymphoma. They provided the latest information on research, clinical trials and treatments.



The Foundation strives to educate the community about cutaneous lymphoma, and provide a space for patients and their care partners to engage with others who have shared experiences. We are very happy to share, based on feedback from attendees, the conference achieved this.

"This was a memorable event. I felt I was a part of a family. Each one was very friendly and courteous. Making physical connections was one of the many highlights of the conference. Hearing the stories shared was such an encouragement. It brought HOPE to the hopeless and discouraged."
– Conference Attendee



Highlights from the 2-Day Patient Conference



We had two wonderful patient panels where the panelists were able to share their experiences and ways they have learned to cope with their disease.



The 2-Day provides an opportunity for attendees to receive a balance of quality of life and clinical information.

We hope to see you next year in California.



"To meet all the patients, to talk about our experiences going through this disease, I learnt so much, most importantly to know that I am not alone. Thank you, thank you again." – Carol B.

Quality of Life...continued from pg 1

lated fatigue, worry over disease worsening, hopelessness or depression with having MF/SS, frustration over the unpredictability of the illness, symptom severity, relationship interference, limitation on daily activities, and burdensome nature of treatment, among others.

The complete 12-item MF/SS-CTCL QoL instrument is available here (pg 9) and may also be accessed online.³ The items are self-scored on a scale from 1-5, with a score of 1 indicating no impact and a score of 5 indicating maximal, negative impact on QoL. For health care providers and patients alike, this rigorous development process helps to confirm that the MF/SS-CTCL QoL instrument will bring all of us closer to the conversations we need to have surrounding the impact of QoL for patients and families living with cutaneous lymphomas.

To further contribute to the body of knowledge on QoL in MF/SS-CTCL, an extensive, systematic review of the literature on QoL in CTCL was reported in 2021 in the Journal of the European Academy of Dermatology and Venereology.⁶ Using the capability and power of multiple databases, such as PubMed, Embase, PsycINFO, and Web of Science, 24 studies were compiled and categorized that involved either standardized instruments or qualitative interviews analyzing the QoL in MF/SS patients. It was found that 18 different questionnaires were used that looked at a wide-range of issues focusing on dermatology, cancer, or generic QoL issues. Of the 24 total studies examined, four of them utilized a qualitative, interview-based or semi-structured method (as opposed to a standardized instrument) to better understand QoL in both early and late stage patients with MF/SS-CTCL.

This extensive review revealed how QoL studies around the globe contribute to an improved understanding of the impact

References

1 In Part 1 of this topic, one research study that explored QoL based upon qualitative interviews with people diagnosed with and treated for CL was discussed.⁴ Please refer to the Cutaneous Lymphoma Foundation Forum, Issue 3 (2022) pgs. 1 and 8 to review that discussion if needed.

2 Online access to the original article is available at <http://www.jmir.org>. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. Copyright©Stacey McCaffrey, Ryan A. Black, Mitchell Nagao, Marjan Sepassi, Gaurav Sharma, Susan Thornton, Youn H Kim, Julia Braverman. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 07.01.2019

3 The MF/SS-CTCL QoL questionnaire may be opened at this link: [jmir_v21i1e11302_app1.pdf](http://www.jmir.org).

4 Bhat T, Herbosa B, Rosenberg A, Sogade B, Jeffe D, Mehta-Shah N, Semenov Y, and Musiek A. Current measures are not sufficient: an interview-based qualitative assessment of quality of life in cutaneous t-cell lymphoma. *Br J Dermatol.* 2021;184(2):310-318. Doi:10.1111/bjd.19298.

5 McCaffrey S, Black R, Nagao M, Seppassi M, Sharma G, Thornton S, Kim Y, and Braverman J. Measurement of Quality of Life in Patients with Mycosis Fungoides/Sézary Syndrome Cutaneous T-Cell Lymphoma: Development of an Electronic Instrument. *J Med Internet Res.* 2019;21(1) doi: 10.2196/11302

6 Ottevanger, R, Beugen, S, Evers, A, Willemze, R, Vermeer, M, and Quint, K. Quality of life in patients with mycosis fungoides and Sezary Syndrome: a systematic review of the literature. *J EADV.* 2021; 35, 2377-2387 doi: 10.1111/jdv.17570

CTCL has on the people diagnosed with, and affected by it. The authors conclude that MF/SS-CTCL affects individuals differently within both early and advanced stages of the illness, but there is no doubt of the impact the illness can have on QoL. QoL in the physical, emotional, functional, and social aspects of a person's life are variably affected; however, the studies corroborated findings that an advanced stage of disease is more directly related to a worsened QoL.⁶

It is both a worthy challenge and goal for health care providers, patients, and care partners to prioritize QoL, keeping it front and center in the treatment plan for MF/SS-CTCL, with the mutual goal of effective treatments alongside improved quality of life. As a patient or care partner, perhaps you can use one or both of the assessment tools shared in this two-part series as a point of reference to begin a discussion with your physician, nurse practitioner, physician assistant, and nurse. Don't hesitate to talk about the QoL issues that affect you and your loved ones' lives, such as your symptoms, your treatments and responses, your financial well-being, your work, your relationships, and your daily functioning. It is important to keep in mind that referrals to social workers, pain management, wound care specialists, financial counselors, or psychologists may have a role in the holistic approach to your care. In short, all the pieces that make up who you are and contribute to your life, your happiness, and your general well-being are important in patient-centered care. Quality of life: keep it front and center as you navigate the challenges of living with CTCL. ❖

Sue McCann, MSN, RN, DNC

MF/SS-CTCL QoL

Please complete these items regarding your experiences over the past 4 weeks.

In the past 4 weeks...

Q1...how much did you worry that your mycosis fungoides or Sézary syndrome may get worse?					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
Q2. ...how often did you feel hopeless because of having mycosis fungoides or Sézary syndrome?					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
Q3. ...how frustrated were you by the unpredictability of mycosis fungoides or Sézary syndrome?					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
Q4...how often did you feel depressed or sad because of mycosis fungoides or Sézary syndrome?					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
Q5...how confident did you feel about managing your mycosis fungoides or Sézary syndrome?					
1	2	3	4	5	
Absolutely confident	Very confident	Moderately confident	Mildly confident	Not at all confident	
Q6. ...how severe were your mycosis fungoides or Sézary syndrome symptoms?					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Not at all	A little severe	Somewhat severe	Severe	Very severe	
Q7. ... how burdensome was your mycosis fungoides or Sézary syndrome treatment?					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Not at all burdensome	A little burdensome	Somewhat burdensome	Burdensome	Very Burdensome	
Q8. ...how much did your mycosis fungoides or Sézary syndrome limit your daily activities (work inside and outside of the house, self-care such as cooking, cleaning, getting dressed, etc.)?					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
Q9...how often did mycosis fungoides or Sézary syndrome (the condition or associated treatment) leave you too tired to work or do daily activities?					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
Q10. ...how much did mycosis fungoides or Sézary syndrome negatively affect your relationships with others close to you?					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
Q11. ...how often did you feel that others do not understand what you are going through with mycosis fungoides or Sézary syndrome?					
1	2	3	4	5	
Never	Rarely	Sometimes	Often	Always	
Q12... to what extent did mycosis fungoides or Sézary syndrome make you feel uncomfortable being around people other than close family and friends?					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Never	Rarely	Sometimes	Often	Always	

The following items are not part of the MF/SS-CTCL QoL, but may provide useful information about the patient's experience:

In the past 4 weeks...

...how much did mycosis fungoides or Sézary syndrome limit your ability to wear clothes you wanted to?					
1	2	3	4	5	
Not at all	A little bit	Somewhat	Quite a bit	Very much	
...to what extent were you able to cope with the daily demands (symptom impact and management, treatment, side effects, appointments, etc.) of mycosis fungoides or Sézary syndrome?					<input type="checkbox"/>
1	2	3	4	5	Does not apply (I don't have symptoms right now)
Not at all	Very little	Somewhat	Quite a bit	To a great extent	

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Frequently Asked Questions

The following questions and responses are from an “Answers From the Experts: Open Q&A” event with Drs. Erick Lansigan and Debjani Sahni.

Is it safe to get ten minutes of full body sun daily?

Sahni: I think it's important and it is how you get the sun. If you imagine the midday sun in the summertime, that's between eleven and three. That's pretty intense. You want to avoid the midday sun, so early morning sun, late afternoon sun, if you get ten minutes, that's a healthy dose. You've got your vitamin D, you've got the effect that you want on your lymphoma from that. Then we typically say sun protection all of the time. So, yes, ten minutes of full sun, but then go to your sun protection for the other times.

Is there any merit to epidermis radiation?

Lansigan: We consider total skin electron beam radiation as a very good treatment for large cell transformation and tumor stage cutaneous T-cell lymphoma. This needs to be given in specialty centers that have electron beam. You have to ask your facility where they deliver this type of treatment and if it's available in your facility. It is a good treatment. It is a very involved treatment. It does require a lot of expertise because there are different schedules that can be tried. We tend to use an abbreviated schedule in the beginning to see what the response would be, because there are side effects to the skin when you do total skin radiation. It's a whole procedure which requires expertise and positioning patients in certain ways so all the electron beams hit the entire skin, and that's why it's called total skin electron beam radiation. It's very effective at controlling the disease. But, often after that radiation is given, some sort of maintenance therapy needs to be given as well, and that maintenance therapy can be ECP, which is extracorporeal photopheresis. Interferon could be used as maintenance if tolerated.

Sahni: Another way to use radiation is just for localized disease. If you don't have tumors all over, perhaps they're just localized to a certain body part or a limb that can be targeted very easily by the radiation. Typically CTCL is very radio sensitive, so you can get very good responses, and because they use superficial electron beam, you can actually radiate that area again if another lesion comes up close by.

How common is it to have lymph node involvement in stage 1A mycosis fungoides?

Sahni: Technically, if you're stage 1A, it means you don't have lymph node involvement. I'm guessing you were diagnosed with stage 1A and you're asking how likely it is. It's extremely unlikely. People with stage 1A have an excellent prognosis and typically the disease isn't the cause of their mortality. Having said that, I would say nothing in medicine is ever 100%. If you see this condition enough, once in a while you'll see something that doesn't behave in the usual way. I'm not saying that you couldn't develop lymphoma involvement in stage 1A disease, and that's why it's important to check with your doctor and have your doctor check you out, but it's highly unlikely.

As more patients are being offered mogamulizumab and we are learning more about its effectiveness, are folks able to take breaks and resume treatment when necessary with success?

Lansigan: It's a great drug, and we're so thankful to have it approved and now being widely used. It's well tolerated, hopefully there are not a lot of reactions and side effects. If someone is having a great response and is looking for a different schedule, I have been able to lengthen the amount of time between doses from every two weeks, and then we might move to every three weeks. This has to be done under close supervision of your oncologist. What I find is that in the community, if a patient is getting this drug through their local oncologist, they're not monitoring the skin as well as in our multidisciplinary clinic. I would make sure that there is good skin follow up with the dermatologist managing you just to monitor if there is any breakthrough of any new lesions on this new schedule. I've been successful doing that with other drugs, including a drug called romidepsin, which was also on a very similar schedule. That is not an antibody treatment, but we were able to increase the intervals for patients who are responding. Since mogamulizumab is a monoclonal antibody treatment, it does stay in the system for longer, up to 90 days, in fact. So I do think it lends itself well to other schedules, but again, under close supervision.

How often and what blood work should I have for maintenance of my mycosis fungoides?

Sahni: In general, when you say maintenance, I'm guessing that you don't have much rash and that the disease is pretty well controlled with whatever treatment you're on. We don't routinely do regular blood tests. The time to do blood tests is if your disease suddenly worsens, it's a much more localized disease and suddenly becomes much more rapid and widespread, or you develop lymph nodes. Some other feature at suggesting a change is typically when we do the blood test, or if you're on certain treatments. For example, if you're on bexarotene or interferon, you would want to do a blood test because those treatments themselves cause abnormalities. But typically, if it's just for the mycosis fungoides, we don't routinely do them.

What are the basic requirements for stem cell transplant? What makes a good candidate?

Lansigan: Usually patients would have failed a number of their treatments or the treatments stopped working, and then need to be considered for stem cell transplant. For the people that we would consider, there are different components. It would be the type of cutaneous lymphoma that they have, cutaneous T-cell lymphoma is what we're talking about, and some of them tend to be more aggressive. You may hear terms like gamma delta, but it is really the behavior of the cancer that we care about the most and its status in regard to prior treatments that have been tried. If you meet that require-

ment of an aggressive lymphoma or what we call a refractory lymphoma that's not responding to prior treatment, then we would consider you for stem cell transplant. I tend to refer our patients to my colleagues who do stem cell transplant, and they take into account a number of considerations, which include comorbid conditions or other medical problems. We take into account age, and we also look at the donor availability. Who is the potential donor? Is it a sibling or is there a match within the national registry of donors. We look to see what capacity there is a match or how many matches are available and what kind of donors are available. Then there are formulas that our group uses that take into account different laboratory values, different patient medical conditions, and then we can come up with a risk score about how patients would do after the transplant. It's a very involved assessment, and this is done at specialty centers that have bone marrow transplant or stem cell transplant available. Then you would have the ability to ask many questions like this directly to the physician. So, in general, that's how we assess our patients.

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Find Your Community!

Are you looking for a way to connect with others who also have cutaneous lymphoma? Or do you have a family member or friend who has the disease and you would like to connect with other care partners?

Then we invite you to join the Cutaneous Lymphoma Community, a place where you can interact online with others facing the same or similar experiences as you.

To learn more, visit
community.clfoundation.org



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