



# Forum

www.clfoundation.org

2016 Issue 3

## INSIDE THIS ISSUE

From the President and the Chief Executive Officer ..... 2

Our Journey with Cutaneous Lymphoma: Charmagne and David Farrar..... 4

A Caregiver's Journey with Cutaneous Lymphoma: Emily Paikin..... 4

Integrative Approach to Treating Lymphoma..... 6

Upcoming Events..... 8

Highlights from NYC 2-Day Patient Conference ..... 10

Your Support..... 12

## Effective Communication With Your Cutaneous Lymphoma Healthcare Team



**Christa Roe, MA, BS, RN, OCN**  
Moffitt Cancer Center  
Tampa, Florida

During my participation in a recent Q&A discussion panel for cutaneous lymphoma patients, sponsored by the Cutaneous

Lymphoma Foundation, questions centered on how to best communicate with the healthcare team arose. This was a chance to explain to the patients in the audience that they are the most important members of their health care team. Effective communication with a patient's healthcare team should help them to obtain goals that are centered on empowerment, engagement, and an improvement in their quality of life.

From the beginning of a patient's diagnosis with such a rare and complex disease, communication is paramount. This is the time for the patient to become an advocate for his or her own care. The recognition that emotions play an integral part in this process is also important. During this time choices become very difficult to make, and the feelings of isolation, fear, and anxiety effect patients, families, and caregivers in different ways.

For a patient to effectively communicate with the healthcare team, he or she should have an understanding that it is their right as a patient to become educated on the disease, treatment options, supportive care services, and the resources that are currently available. Each patient who is diagnosed with cutaneous lymphoma has a unique set of signs and symptoms and often times, these change during the course of the disease. The patient should keep a notebook for documentation of signs, symptoms, tests, and questions. This allows for more patient information to be shared with the healthcare team. Ultimately, because of effective

### Questions Patients Should ask their Healthcare Provider

- What type of cutaneous lymphoma do I have?
- What is the stage of my disease?
- Has it spread to other areas of my body?
- What tests will I need?
- What treatment will I need?
- What type of physician should I see?
- Should I obtain a second opinion?
- Is my cutaneous lymphoma genetic? Do my family members need to be tested?
- What is the prognosis?
- Is there a cure for cutaneous lymphoma?

Effective Communication...continued on page 9

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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.

**From the Chief Executive Officer**



**Susan Thornton**

Seth Godin is a bestselling author who writes about the post-industrial revolution, the way ideas spread, marketing, quitting, leadership and most of all, changing everything. You might be familiar with his books *Linchpin*, *Tribes*, *The Dip* and *Purple Cow* (one of my favorites). In a recent blog post, Seth offered some good advice related to making a decision based on new information. He said:

*Sure, I decided that then, when I knew what I knew then. And if the facts were still the same, my decision would be too. But the facts have changed. We've all heard them. New facts mean it's time for me to make a new decision, without regard for what I was busy doing yesterday....*

Sometimes when living with a disease like cutaneous lymphoma, we can only make decisions based upon the information we currently have. Which is why it's important to stay informed about research, clinical trials and what new treatment options might be available to us. Charmagne Farrar speaks about this in her article. She and her husband David, learned something new throughout their journey and incorporated that into their discussions with their healthcare team, resulting in David trying different treatments to manage and clear his disease. As most of us know, this disease can be quite frustrating to deal with, especially when treatments don't seem to be working or we have to try a treatment for a long period before determining its time to try something different. It is the Foundation's core mission to provide up-to-date information through this newsletter, the Online Learning Center and the live educational events to help empower you to make the right decisions for yourself.

Speaking of making decisions, the critical nature of open communication and dialogue with your healthcare team can often translate into less frustration with the disease or at the very least, the satisfaction that you, as the patient, are proactive in managing your specific situation. In the long run, this is a marathon which sometimes requires slogging through day in and day out. Not always easy. And if you can find a way to still enjoy your life, enjoying every day to the best of your capacity makes the challenges a little

*From the CEO...continued on page 7*

**From the President**



**Joe Eischens**

Hello Patients, Caregivers, and Friends!

I hope this finds you all well and reflecting on all of the things for which we can be thankful. During this special time of the year I am particularly thankful for all of you and the support you have given the Foundation over this past year. Your kindness and generosity enable us to be responsive to your needs and to provide the impressive array of information and services that the Cutaneous Lymphoma Foundation is proud, happy and humbled to make available to all of you.

In this edition of the Forum our theme is "Awareness and Engagement." Once again, in these pages you will find specialized information to help all of you cope day to day with this disease. In this issue we offer up-to-date articles about integrative medicine and its place in cancer treatment and a "how to" tutorial on best communication techniques with your healthcare team. Additionally, I know you will be moved and impressed with the inspirational stories from two of our treasured caregivers. This is the AWARENESS part of this newsletter.

Our personal journeys are filled with daily struggles, pain, and sometimes desperation, but those "down times" are frequently overcome by experiences of triumph and hope. It is these hopeful stories that continue to inspire us here at the Foundation. They drive our desire to fulfill our mission of funding and encouraging remarkable research and to provide a wealth of services, all with the goal of eventually finding a cure for this disease. We cannot meet this goal without the ENGAGEMENT of our amazing doctors and researchers, Board of Directors, Foundation staff .... and you, our supporters.

Many of you received the Foundation's Annual Report recently. You learned that through the engagement and extremely hard work of so many, we have had a great year at the Foundation. We hosted 14 patient educational events all over the United States. We provided \$150,000 to amazing research through our CLARIONS Research Grant and Young Investigator Award programs, and we thoughtfully answered your hundreds of calls and requests for information and support. And, of course, we

*From the President...continued on page 7*

**Forum**

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Check out the latest news and information from the Cutaneous Lymphoma Foundation by liking us on Facebook!

**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.

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



## Our Journey with Cutaneous Lymphoma: Charmagne & David Farrar



**Charmagne & David Farrar**  
Shelbyville, TN

cancer, although not curable. Well, it couldn't be too bad if we were simply rubbing creams on and going to a tanning bed, could it?

In August 2012, we attended a PEF in Atlanta, which I had found on the Foundation's website. We went with David "kicking and screaming" that this was just a waste of time. We have since attended three more conferences since that one, each without "kicking and screaming."

While at the Atlanta conference, we learned that he had folliculotropic mycosis fungoides (FMF), and that systemic treatments would work better on FMF, as opposed to the creams and light therapy he had since been prescribed; our Vanderbilt doctor concurred. David started Targretin the next week. Because of Targretin, his thyroid quit working properly so he started on a medication for this. Itching became his constant companion so he began taking Gabapentin to relieve the itching. Although the medication often made him drowsy, life was still pretty good.

We attended a CLF conference in Kansas City, and one in San Diego the following year. In Kansas City we learned about photopheresis. We returned and presented this suggestion to our doctor at Vanderbilt, who was receptive to the idea. This was June of 2014; by August of that year, we were traveling to Vanderbilt two days a month for David's photopheresis treatments.

*"It's not a sprint, but a marathon."*

These are words spoken by Susan Thornton at every Cutaneous Lymphoma Foundation conference we have attended. While they didn't have much personal meaning at the Atlanta Patient Educational Forum (PEF) in the fall of 2012, the words rang true in Chicago 2016.

My husband, David, was diagnosed by Vanderbilt Dermatology in June 2012. The phone call came about his biopsies approximately three weeks after they were performed. The doctor said the words, "T-cell lymphoma."

We researched online trying desperately to learn as much as we could about this cancer that was on the skin, but not skin cancer. We were assured this was a perfectly manageable

**It is a journey we didn't plan, but it is one that we now feel equipped to navigate. Slow down and breathe. Remember a wise woman once said, "It is a marathon."**

During the latter part of 2015, however, the outbreaks spread all over his body and the itching was life-altering. In the spring of 2016, we received our Forum Newsletter from the Foundation. There was an article about a study being conducted in Boston using full body low dose radiation. The results were mostly positive and patients participating in the study were having lengthy periods of remission. My husband spent a lot of time online researching this treatment and was determined it would help him.

We presented it to our Vanderbilt team and once again, they were receptive and optimistic. On June 1, 2016, he started radiation; he completed it on June 15. We added a very capable radiation oncologist to our treatment team. David was able to attend the Foundation's conference in Chicago at the end of June. I was skeptical, but this time HE insisted on attending.

Since radiation, he has lost his hair, but he has gained restful nights, alertness, and a body without sores. For the first time in four years, he was able to shave with a razor. We are currently doing photopheresis two days a month to strengthen his immune system. We know this is not a cure. However, we have had two months of no itching and no harsh systemic drugs.

The Cutaneous Lymphoma Foundation's website, publications, and conferences have provided us with the tools and information we needed and has allowed us to help direct David's treatment. In addition, networking at the conferences has been invaluable. We have taken time for "us" more than ever before. We have traveled; we have celebrated the marriage of our eldest son; we have welcomed his first child into our family. Was it difficult at times? Yes. Have we been scared? Yes.

My advice to others on this journey would be to educate, advocate, and live. Don't just exist but live. Take time for what you need to feed your soul; then you will have the mental and physical strength that your partner needs you to have.

This disease has definitely changed our lives, but we have always found advocates in our healthcare team and in the Cutaneous Lymphoma Foundation. They have propped us up when we needed it.

It is a journey we didn't plan, but it is one that we now feel equipped to navigate. Slow down and breathe. Remember a wise woman once said, "It is a marathon." 🐾

## A Caregiver's Journey with Cutaneous Lymphoma: Emily Paikin



**Emily Paikin**  
New York, NY

In March, 2014, I received a phone call that no one ever wants to get. It was my fiancé, Brett Weiss, calling to tell me he had just been diagnosed with a cancer called mycosis fungoides (MF). He had just returned home from a follow-up appointment with his dermatologist that he had originally thought nothing of. I was at work, and everything became a blur. I ran out the door immediately, jumped in a taxi and rushed home with tears streaming down my face. At that moment, I knew nothing. I didn't know what kind of cancer mycosis fungoides was, how serious it was, or what was in store for our future. When I got home, all I wanted to do was hug Brett and not let go.

As most people do nowadays, we jumped on our computers and Googled ourselves into a frenzy. We prayed to come across positive findings, but the internet is filled with worst case scenarios. We both knew we needed to stop and learn more about it from professionals and reputable sources. After a few hours passed, and we had spoken to some doctors and talked things through with each other and with family, we were able to compose ourselves and think more rationally. The first few days were definitely hard, but as we learned more about MF and Brett's stage 1A diagnosis, we were reassured that this was something that could be treated and managed. It would require some small life alterations, but for the most part Brett would be able to live a long and normal life.

As it happens, our wedding date was less than 5 months after Brett's diagnosis, and we used that as major motivation to combat his patches and come to terms with this change in our lives. We were planning a 3 week Hawaiian honeymoon, and I knew that the last thing that Brett wanted was to have

to apply a cream or visit a phototherapy center while we were in paradise. He diligently used the cream and went to phototherapy appointments, and by our wedding day, the patches were virtually gone.

As Brett's wife, I am continually amazed at his strength and positivity on a daily basis. Since being diagnosed, the patches on his skin have disappeared and reappeared on a couple of occasions. He is fortunate that the topical steroids generally eliminate the patches fairly quickly. With each recurrence, we feel more confident in handling this disease, and I am always there to assure him that he can tackle it.

I wouldn't exactly call myself his caregiver, but as his wife and as someone who loves him and wants the very best for him, I work with him to maintain a healthy lifestyle by way of eating healthily, working out and staying busy. We do make time every couple of weeks to do a skin check to make sure that old patches haven't come back and that no new ones have appeared.

Brett is a true inspiration. He is almost always in a good mood and makes it his daily mission to make other people laugh and smile. I rarely see him worrying about his MF, which puts my worry about it at ease. I admit there are times when I probably think about it more than he does, but I usually try to avoid bringing it to his attention because I don't want him to dwell on it. However, I am always available if he ever wants to talk about it or share new research that he has found.

Brett and I are in this 100% together. My best advice to any spouses or caregivers going through the same thing is to live life to the fullest, practice gratitude and enjoy being together. Oh, and to avoid Googling. If you have any questions, your doctors or the Cutaneous Lymphoma Foundation website are your best resources. 🐾



## Integrative Approach to Treating Lymphoma



**Dr. Arvin Jenab, ND**  
Susan Samuelli Center for  
Integrative Medicine, UC Irvine  
Irvine, CA

As you probably already know, lymphomas are a unique group of cancers that are characterized by the involvement of our immune cells. Immune cell cancers pose a

unique challenge in alternative and integrative medicine, whose treatments have traditionally focused on stimulating and enhancing the immune system – in the case of immune cell cancers, stimulating the lymphocytes can potentially cause more harm by causing further proliferation and growth of the cancer cells. In the attempt to develop effective strategies to support patients with lymphomas, specific nutrients and herbs have been identified, targeting lymphoma based on several important hypotheses, which inform our current understanding of these diseases and the factors that contribute to its onset and progression. These hypotheses include:

### 1. Chronic Antigenic Stimulus

Chronic antigenic exposure and stimulation of the lymphocytes may result in clonal proliferation of the immune cells. Source of antigen can be environmental or internal with chronic exposure acting as a persistent antigen, which, in a stepwise process, leads to aggregation and proliferation of lymphocytes and an accumulation of mutations in oncogenes, suppressor genes, and signal-transducing gene, increasing the risk of lymphoma development.

This hypothesis is supported by a number of observations: Individuals exposed to environmental toxins and chemicals such as pesticides have been observed to have a higher incidence of lymphoma; Individuals who have an underlying viral infection are at a higher risk of developing lymphoma; Compromised digestive health which results in hyper-permeability (leaky gut) can act as a source of antigens which are able to enter the bloodstream and stimulate the immune system.

### 2. Chronic inflammation

A direct link between inflammation and lymphomagenesis has been observed and supported by large epidemiological studies showing a consistent

risk increase of lymphoma associated with certain autoimmune/inflammatory conditions. Disease severity and the degree of inflammatory activity determined risk of lymphoma development. On a systemic level, this is observed in the association between lymphoma and certain autoimmune conditions. Locally, there is strong evidence for inflammation playing an important role in the progression of lymphoma and anti-inflammatories have been shown to decrease disease progression.

In support of this hypothesis, studies have shown that high levels of serum CRP, a marker for inflammation, is strongly associated with progression of lymphoma. CRP can be an effective marker to track in order to evaluate patient's response to treatment and prognosis. Additionally, it has been demonstrated that the risk of developing lymphoma increases substantially when autoimmune conditions such as rheumatoid arthritis are poorly managed and presenting with increased inflammation.

### 3. Apoptosis failure

Although listed as a distinct category or hypothesis, it is important to note that apoptosis (cell death) failure often may be secondary to chronic antigenic stimulation and chronic inflammation which result in mutations in oncogenes and suppressor genes. Additional information is emerging that is looking more closely at epigenetic markers and their association with decreased apoptosis. This new research may lead to more targeted and individualized assessments and treatments, and improved outcomes for patients at risk of developing lymphoma.

These hypotheses inform the strategy and the treatments that a naturopathic doctor may recommend.

#### An effective strategy will:

- Decrease chronic antigenic stimulation by minimizing exposure to chemicals and pesticides while enhancing the body's ability to process and eliminate toxins
- Identify underlying viral infections (eg. EBV, Hepatitis virus, H. Pylori) as well as any autoimmune conditions, and ensure that treatments are considered in patients who test positive
- Improve intestinal health to decrease hyper-permeability and repeated exposure to antigens that are of intestinal origin while maintaining a healthy microbiome
- Decrease local and systemic inflammation using anti-inflammatories and by modulating inflammatory

- pathways using targeted nutrients and herbs
- Provide anti-oxidant support and ensure adequate supply of nutrients that will protect cells from free-radical damage and enhance apoptosis
- Provide adjunct treatment to patients undergoing chemotherapy and/or radiation therapy in order to enhance treatment effectiveness and more importantly to protect organs and systems from some of the undesirable side effects

#### What can you do today?

- Increase exercise and lead an active lifestyle – 20-30 minutes a day 3-4 days per week is all you need.
- Eat a diet that is primarily vegetarian with occasional healthy, organic meats.
- Eat a low-calorie diet – studies consistently show that a low-calorie diet improves outcomes in lymphoma patients.
- Increase colorful herbs, vegetables and spices – especially important are dark berries, green leafy vegetables, sprouts, turmeric, ginger and green tea.
- Take care of your health – if you have or had an underlying condition or other symptoms such as digestive symptoms, skin rashes, headaches, etc. seek care and address these – underlying conditions impact your immune system and may be indicative of factors that are contributing to your lymphoma.
- Don't do it on your own – your care team is there to support you – there is a vast amount of information that informs treatment – the more individualized your treatment the more effective it will be.



## From the CEO...continued

easier to deal with. Emily Paikin shares her wisdom on how she and her husband Brett have done just that.

There is much going on in the area of research, and new clinical trials focused on our disease is giving many reasons to hope. By the time you read this newsletter, the 3rd (ever) World Congress of Cutaneous Lymphomas will have been held in New York City, and our 2-Day Patient Conference immediately following will be over. Make sure to check out the videos from the 2-day conference in the Online Learning Center. There might just be some new facts that could impact your thinking and decisions about what next steps you can take in managing your disease in collaboration with your healthcare team. We will also be sharing a synopsis of the meeting highlights in the next issue of the Forum.

As always, we love to hear from you. If we didn't have the chance to connect with you over the course of the year, we hope you will consider joining us in 2017 for one of our live events or on a webcast. Let us know how we can serve you better as you continue to expand your knowledge and your zest for life!

Be well,

Susan

## From the President...continued

do all of this on a limited budget. Yes, we do have wonderful corporate partners on this path to a cure, but we also need your support more than ever.

In this season of giving, please consider making a donation to the Cutaneous Lymphoma Foundation. Our staff would love to assist you with discovering the most effective and beneficial method to give; either through personal donations, wills/trust designations, memorials, or any other avenue that makes the most sense for you and your family. We want and need you to be ENGAGED so that we can all, one day, proclaim, "I AM CANCER FREE!"

Take care.

Joe

## Cutaneous Lymphoma Patient Educational Opportunities

The Cutaneous Lymphoma Foundation offers free Patient Educational Forums throughout North America providing an opportunity to:

- Receive the latest information about cutaneous lymphoma and learn about treatment options from experts in the field.
- Learn what's new in cutaneous lymphoma research and clinical trials.
- Q & A sessions - probably the most popular portion of the day. Have questions about the different types of cutaneous lymphoma, treatments, or daily living? The Q & A sessions provide you an opportunity to ask in a relaxed and friendly environment.
- Meet and network with other individuals affected by cutaneous lymphoma. Being diagnosed with or caring for an individual with a rare disease can be lonely, meet others who know and understand what you are going through.
- Learn about available resources for treatment and support.

*We hope to see you at an event soon!*

### Patient Networking Groups

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

**CLF-DC**

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

**CLR-LV**

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

**CLF-NYC**

New York, New York  
www.clfoundation.org/CLF-NYC

**CLF-OR**

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

**CLF-SLC**

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

### Upcoming 2017 Events\*



**February 2017: Orlando, FL**  
Cutaneous Lymphoma Foundation  
Answers from the Experts...Live!



**April 2017: Toronto, ON, Canada**  
Cutaneous Lymphoma Foundation  
Patient Educational Forum



**May 2017: Memphis, TN**  
Cutaneous Lymphoma Foundation  
Patient Educational Forum



**June 2017: Los Angeles, CA**  
Cutaneous Lymphoma Foundation  
2-Day Patient Conference

**For more information and to register for these events, visit [www.clfoundation.org](http://www.clfoundation.org) or call 248.644.9014, ext. 4.**

*\* Dates and venues are subject to change. Please check website for most up-to-date information.*

The Cutaneous Lymphoma Foundation extends its thanks to the following generous supporters of our events:



## Effective Communication...continued

### The Roles of your Cutaneous Lymphoma Healthcare Team

|   |  |
|---|--|
| Dermatologist   | A physician who specializes in diagnosis and treatment of skin diseases. Some dermatologists specialize in treating cutaneous lymphoma. These physicians also obtain skin biopsies for a confirmatory diagnosis of cutaneous lymphoma.                                   |
| Medical Oncologist/Hematologist                             | Trained in internal medicine and in diagnosing and treating cancer or blood cancer with chemotherapy, biological therapy and other treatments. They often manage the patient's course of treatment, especially when the patient has systemic involvement.                |
| Radiation Oncologist  | Physician who specializes and administers radiation to treat cancer.   |
| Oncology Nurses and Other Health-care Professionals         | These professionals may specialize in working with specific types of cancer and specific treatment modalities such as photopheresis or dermatology. Registered nurses, clinical nurse specialists, advanced practice nurses, chemotherapy nurses, radiation therapist.   |
| Pharmacist  | An expert in medications who understands and can advise on the use and interactions of medications, and help doctors review allergies and drug-drug interactions (which are common).   |
| Psychosocial Therapist                                      | This is a counselor who helps the patient navigate through the emotions after diagnosis.   |
| Nutritionist  | This person aids in exploring the foods and nutrients the patient needs to sustain health through treatments.  |
| Social Worker   | This person helps manage the emotional toll that the disease can take. They may help to provide support, development and empowerment.  |
| Oncology Social Worker/Clinic Coordinator/Patient Navigator | This person is tasked with looking at logistics and helping patients plan their course of treatments. This is a person who can help guide patients when they face treatment challenges with insurance coverage, financial support, travel issues, etc.                   |
| Other Patients and Resources                                | Those individuals diagnosed cutaneous lymphoma. The Cutaneous Lymphoma Foundation is an excellent resource for helping patients connect with others. The Foundation website is a good place to start ( <a href="http://www.clfoundation.org">www.clfoundation.org</a> ). |

communication with the healthcare team, the patient's plan of care becomes personalized.

The importance of finding a multidisciplinary team of experts who specialize in the disease, or a healthcare provider who is a leader and has experience in management of cutaneous lymphoma, decreases the chances of patients lost in a critical transition. Patients should advocate for interdisciplinary communication between their generalist, oncologist, and dermatologist. This improves satisfaction, and ensures continuity and safety of care for patients. Understanding the different roles your healthcare team play in your care can be helpful when seeking treatment.

Often times, patients have gone years without a diagnosis of cutaneous lymphoma and they become frustrated because they do not have answers. Studies have shown that patients who communicate effectively from the onset of their disease and during their cancer care are more satisfied, feel more informed, and have an overall improvement in quality of life. Communication with the healthcare team is a constant and evolving process. This should start once the patient has been diagnosed and continue for the entirety of their journey. 🌟

As a follow-up to the 3rd World Congress of Cutaneous Lymphomas, the Cutaneous Lymphoma Foundation held a special 2-Day Patient Conference in New York City.

Attendees heard from international cutaneous lymphoma specialists, researchers, and clinicians who are taking steps to better understand and treat the disease. We would like to thank the following medical professionals for joining us and sharing their knowledge: Emilia Hodak, MD; Steven Horwitz, MD; Ellen Kim, MD; Lanny Kirsch, MD; John O'Malley, MD, PhD; Lauren Pinter-Brown, MD, FACP; Alistair Robson, BSc, MBChB; Julia Scarisbrick, MBChB, FRCP, MD; Marianne Tawa, RN, MSN, ANP; and Maarten Vermeer, MD, PhD.

In addition to the clinical presentations, guests were encouraged and inspired to live in positivity through personal stories from Brett Weiss, Steven Brown and Susan Thornton. Rounding out the event was Cathy Leman, MA, RD, LD, who demonstrated a three-step method for aligning individualized nutrition with personal health goals.

On Saturday night, guests were invited to attend our "Celebration of Life" cocktail reception. This year, we invited our CLARIONS Research Award recipients to mingle with patients, caregivers, physicians and sponsors for one-on-one discussions about the exciting research they are completing. Guests also participated in installation artist Candy Chang's "I wish I could..." public art exhibit, which was inspiring and moving.

The weekend was very informative and filled with hope for all affected by cutaneous lymphoma. 🌟



Dr. Larisa Geskin, host of the World Congress, welcomed the 2-Day Patient Conference attendees.



Prof. Maarten Vermeer and Dr. Julia Scarisbrick take questions about the Cutaneous Lymphoma International Consortium.



Dr. Ellen Kim (left) takes questions from attendees during a conference break.

Clinical Panel on treatments: Ellen Kim, MD; John O'Malley, MD; and Marianne Tawa, RN, MSN, ANP.



Clinical breakout group with Dr. Lauren Pinter-Brown.



Rare Variants of Cutaneous Lymphoma Clinical Panel: Emilia Hodak, MD; and Steven Horwitz, MD.



Brett Weiss opened the conference with his personal story of being diagnosed with cutaneous lymphoma.



Dr. Larry Kirsch shared exciting new advances in diagnostic tools.



CLF's Board President Joe Eischens (right) and Community Director Tina Collins (center) share a moment with reception guest.



Alistair Robson, MD (pictured second on right) with conference attendees during lunch break.



Conference attendees adding their "wishes" to Candy Chang "I wish I could..." board.

# Update from the 2016 2-Day Patient Conference 3rd World Congress of Cutaneous Lymphoma New York, NY



CUTANEOUS LYMPHOMA FOUNDATION

PO Box 374  
Birmingham, MI 48012

**TIME SENSITIVE MATERIALS ENCLOSED**

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

***Your support*** allows us to provide quality information through our Online Learning Center and free publications.

***Your support*** allows us to support research initiatives and bring cutaneous lymphoma experts to our live events.

***Your support*** provides assistance in finding beneficial care and treatment options in response to your phone calls and e-mails.

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

Please continue to support the Cutaneous Lymphoma Foundation by using the enclosed envelope or online at [www.clfoundation.org/giving-online](http://www.clfoundation.org/giving-online). 

