

Cutaneous Lymphoma - International Collaboration - Meeting Minutes

Meeting Date: June 12, 2023

Link to Recording: <https://youtu.be/URMMJrpFuks>

Attendees:

Susan Thornton, Cutaneous Lymphoma Foundation, US
Holly Priebe, Cutaneous Lymphoma Foundation, US
Antonella Rizza, Lymphoma Canada, Canada
Berardino Porfirio, Patient Group With Lymphoma/Italian Association against leukemia, lymphomas and myeloma, AIL, Italy
Rita O. Christensen, LYLE, Denmark
Kathy Redmond, Strategic Consultant, Switzerland
Guy Bouguet, ELLyE, France
Enzo Bottazzi, Patient Advocate, Italy
Jauquin Diez, AELIC, Spain
Ton de Leeuw, Skin Lymphoma Foundation, the Netherlands

Recap of Workshop held in October 2022

The Workshop was a meeting of member organizations of the Lymphoma Coalition for the purpose of collaborating with each other in order to better serve cutaneous lymphoma patients within their own countries. Some of the goals of the collaboration include:

- Leveraging existing resources and information
- Improving the ability to connect patients to each other
- Creating a larger pool of patients to participate in clinical trials, surveys/data collection
- Alleviate the need for multiple cutaneous lymphoma-specific organizations especially in countries where the number of patients is very small

Overview of Upcoming Events and Current Projects

- International Patient Conference - September 9, 2023 - The CLFoundation is holding its third International Patient Conference virtually in September. Other Cutaneous Lymphoma - International Collaboration members are invited to participate in the conference and/or host a networking group.
 - Conference will be held in the European and US Pacific time zones
 - *Basics of Cutaneous Lymphoma* sessions will be offered in Spanish, Portuguese and German languages with clinicians from those countries
 - Live Q&A with two clinicians
 - Patient networking opportunity in their own language
 - Will introduce patient survey opportunities and the importance of patient data collected and encourage attendees to participate
 - Lymphoma Coalition Patient Survey - launching in 2024 - focuses on impact of living with lymphoma (hematology)

- Global Skin GRIDD Survey - focuses on the impact of living with a skin disease (dermatology)
- European Cutaneous Lymphoma Scientific Meeting - September 2023 in the Netherlands
 - A patient program will be held at the meeting's conclusion on September 23, 2023. The meeting is in collaboration with the Netherlands Skin Lymphoma Foundation and will be live-streamed. The program will focus on a recap of the Scientific Meeting.
- Cutaneous Lymphoma - International Collaboration Workshop - October 19, 2023 (afternoon) in Madrid
 - To be held in-person at the end of the Lymphoma Coalition's Annual Global Summit
- Related CL Foundation projects
 - Creating an online platform to connect collaborative groups for sharing content, communication, resources and updates
 - Providing CL Foundation website content for other organizations to use
 - Currently providing to AELIC to translate for their website
 - Need to work through the logistics of sharing to ensure that the content is clinically appropriate and accurate for the country where it is shared

Open Discussion

- To help raise awareness of rarer lymphomas like cutaneous lymphoma, the Lymphoma Canada is developing a "Did You Know?" campaign. The idea is to use a social media/infographic type format to provide basic disease information. Working on the project collaboratively could provide an opportunity to offer messaging globally and in more languages. A goal of the project is to help reduce the time it takes to receive an accurate diagnosis and help avoid mis-diagnosis which are common issues for CTCL patients per previous Patient Surveys.
- Bernardino supports having a platform where individual organizations can share their cutaneous lymphoma specific resources, like webinars, so that they are more visible to others to find and use.
 - CL Foundation hopes to offer a space on its website for individual pages by country where collaborative member groups can be listed and linked to so that patients can more easily find available resources in their own country
- To help raise awareness in Denmark, LYLE has recently published a book of patient stories and a leaflet and hosted a webinar in order to raise awareness. It's a challenge to raise public interest in disease awareness in the country, yet the need for information exists. Being able to access existing CTCL information would be helpful.
 - Rita will provide access to the Danish webinar to CL Foundation for use in the International Patient Conference.
- The value of the collaborative group is that while CL Foundation can help create a "library" of content and provide information related to clinical trials, research, HTA approvals, the group members are the experts on their countries health care systems, available specialists and resources.

- The Lymphoma Coalition has a project to create a “global landscape” of cutaneous lymphoma: where are patients located, who are the specialists, what & where clinical trials are available, etc - in order to be proactive in efforts to benefit patients rather than reactive
- Kathy asked if other Cutaneous Lymphoma - International Collaboration group members and the Lymphoma Coalition would be attending the Workshop in October in order to provide some continuity with the 2022 meeting. After a brief review of who attended it seemed promising that a representative from each would be in attendance.
 - Recommendation to share the report from the 2022 meeting prior to this year’s in order to continue the conversation and build on it rather than starting over
- Kyowa Kirin, a pharmaceutical company (mogamulizumab), is planning a global awareness campaign for cutaneous lymphoma to launch in February 2024 around Rare Disease Week.
- The crossover that occurs between hematology and dermatology is creating a challenge for FDA-approval of a promising new treatment in the US
 - The treatment is a topical sensitizing agent which is then exposed to fluorescent lightbox rather UVB which can help eliminate risk of long-term skin cancer
 - Hematologic reviewers are not always familiar with skin-directed therapies.
 - The FDA is no longer accepting the current protocols and requiring an additional Phase 3 trial. The cost of trial is prohibitive.
 - Because treatment approvals in Europe frequently follow the FDA lead, this could impact its potential availability outside of the US.
 - This would be a good topic of discussion for the Madrid workshop, so that the European/Canadian groups could become aware of the arguments and become prepared for an aligned and consistent approach regarding why topical treatments therapies are important.
- The Skin Lymphoma Group is publishing informational cards with basic cutaneous lymphoma and treatment information for patients. They are in Dutch and will be translated into English and possibly Arabic.
- Enzo offered to help with translation projects.
- Currently, there is not a “Cutaneous Lymphoma Day” in the US. Typically we tie into the existing lymphoma and/or skin disease awareness days
 - Educating dermatologists so that they are more aware of the disease and better able to recognize when it might be present is an important step in reducing the amount of time it takes to get an accurate diagnosis