

cutaneous lymphoma International collaboration of patient organizations

6th October 2022

Porto, Portugal

SUMMARY REPORT

Question: How to best serve cutaneous lymphoma patients world-wide.

With this in mind, the Cutaneous Lymphoma Foundation convened a meeting of representatives of patient organizations across counties with interest in cutaneous lymphoma.

Meeting Goals:

- Learn from each other's experience in supporting and advocating for people affected by CL
- Explore the value of international collaboration between patient organizations with an interest in CL and agree where to focus this collaboration
- Determine next steps

The meeting was attended by 11 participants representing 9 countries

Organization	Name	Country
AELIC - Cutaneous Lymphoma Patient Org. Spain	Joaquin Diez	Spain
Association Portuguese Contra a Leucemia (APCL)	Lara Cunha	Portugal
Associazione Italiana Contro Leucemie Linfomi E Mieloma	Enzo Bottazzi	Italy
Cancer Patients Finland	Matti Järvinens	Finland
CL Foundation	Holly Priebe	Global/US
CL Foundation	Susan Thornton	Global/US
CL Foundation Netherlands	Ton deLeewu	Netherlands/Belgium
CL Foundation Netherlands	Mieke deLeewu	Netherlands/Belgium
Lymphoma Action	Tara Steeds	United Kingdom
Lymphoma Switzerland	Rosmarie Pfau	Switzerland, Germany & Austria
Lymphoma Coalition	Lorna Warwick	Global
Redmond Consulting - Facilitation	Kathy Redmond	Facilitator



Existing resources across organizations

- A Patient's Guide to Cutaneous Lymphoma - translated
- Treatment Guide
- Fast Facts (multiple diagnosis) - translated
- Webinars
- Videos
- Peer-to-Peer Community/Facebook groups
- Treating Centers and Physician Lists
- Cutaneous Lymphoma specific research funding

Identified Key Challenges of people affected by cutaneous lymphomas

Nature of condition

- Many sub-types – some very aggressive and life-threatening, others with limited impact on patients' life
- Needs vary considerably
- Differences in terminology used
- Confusing terminology
- Many patients are elderly
- Some find it difficult to talk about their condition

Rarity of condition

- Lack of awareness
- Difficult to find patients (data privacy laws)
- Need clinicians' help to identify patients but they are often too busy to help and not all of them are willing to refer patients to groups

Diagnosis

- Presenting symptoms usually seen by a dermatologist who are not familiar with the condition
- Mis-diagnosis and late diagnosis are common

Identified Key Challenges of people affected by cutaneous lymphomas (cont.)

Treatment and care

- No curative treatment
- Huge variety in treatment options between countries
- Most patients are treated by dermatologists
- Lymphoma groups do not have existing relations with dermatologists
- Difficult to know who to connect to
- Not all dermatologists are familiar with CL
- CL should be treated in a specialist centre – no agreed criteria for a specialist centre
- Some patients have to travel long distances to a specialist centre

Research

- Lack of funds for different types of CL research
- Lack of CL research
- Little incentive to do CL research
- Low recruitment into clinical trials especially for rarer CLs
- Comparators used in some US-based CL studies are not always approved in Europe which leads to access problems

Information and support

- There is a lot of patient information available but can be difficult to find and is not always available in the language of the country
- Some lymphoma groups provide limited information about CL that is embedded in general information about lymphoma
- There is a need for simple and easy-to-understand information for people with health literacy challenges (e.g. animations, cards etc)
- Peer to peer support is difficult to establish as there are so few patients and so many different CL subtypes
- Needs of family members are often overlooked

Identified Key Challenges faced by patient organizations in CL

- Few dedicated CL patient organizations
- Difficult to sustain a CL specific patient organisation due to lack of funding and people
- CL is not a priority for mainstream lymphoma organizations – its difficult to invest in services for this group of patients when there are many other patients with needs
- Lack of evidence to support CL patient advocacy
- Existing CL resources not easy to find
- Its not easy to find CL patients and for CL patients to find the groups

Prioritized Key Challenges faced by patient organizations in CL

1. Find patients and for patients to find PAGs
2. Lack of awareness about CL and available resources to support patients and their families
3. Develop easy-to-understand information about CL in different formats
4. Identify specialists who are treating the condition and to connect with them
5. Build and maintain sustainable organizations that are capable of meeting the needs of people affected by CL
6. Increase CL research in order to:
 1. Develop new treatments
 2. Better understand the nature of the condition
 3. Uncover the true burdens associated with living with the condition
 4. Generate evidence to support advocacy

Top Priority: Establish an International Cutaneous Lymphoma Patient Network

- Participants agreed that it would be valuable to establish an International CL Patient Network that would:
 - Connect interested groups via a Facebook group or What'sApp
 - Facilitate the sharing resources that can be translated and adapted to the country needs
 - Establish a digital repository of existing resources
 - Meet annually to learn and share experiences (e.g. Following the Lymphoma Coalition's meeting)
 - Support the establishment of groups where they do not already exist
 - Develop new easy-to-understand resources that could help people with health literacy problems more easily understand the condition (e.g. Animations)
 - Facilitate the establishment of support groups in different languages
 - Develop a common approach to finding CL patients through clinicians and specialist centres
 - Launch an international symptom campaign to promote more timely diagnosis
 - Put pressure on companies such as Kyowa Kirin to involve patients in the co-creation and roll-out of their campaigns
 - Provide input in the Cutaneous Lymphoma Foundation's virtual International Patient Conference
 - Generate and share global patient data on CL
 - Facilitate connections with CL specialists including dermatologists and haematologists
 - Increase specialists' awareness of all the patient groups that have an interest in CL
 - Establish a formal connection with the professional societies active in the CL setting (e.g. EORTC Cutaneous Lymphoma group and the International Society for Cutaneous Lymphomas)
 - Promote CL research
- The Network can be expanded by involving other interested lymphoma groups (e.g. Sweden & Denmark as well as online CL Facebook groups)

Next steps

- Susan and Lorna are to discuss the steps needed to set up an International CL Patients Network and potential actions needed in 2023 to ensure the success of the Network
- The proposal will be presented during a follow up call with interested groups in December 2022 or January 2023
- Susan to investigate potential funding for the Network's activities in 2023