

NODE NEWS

MEMBER NEWSLETTER | JANUARY 2019

LYMPHOMA
COALITION

Worldwide Network of
Lymphoma Patient Groups



Dear LC Members,

The Lymphoma Coalition has a long, fruitful history and is well-respected as a valued partner by many. Numerous people have reached out over the last month, ensuring I know about their activities and seeing how we can continue to work together. This reinforces to me how strong the Coalition is and the valuable role it plays in the cancer community. I look forward to additional conversations over the coming months and welcome the opportunities to chat. As I continue to learn more about the scope of support offered to lymphoma patients globally by member organisations, my respect grows for each of you due to your dedication and willingness to help patients when they need it most.

Through these discussions, it has come to light that not all members know much about the alliances LC has formed. More information regarding these alliances will be included on the website in the near future, and highlights included in the newsletter as events happen.



Anita Waldmann, Guy Bouguet, Natalie Dren, Lorna Warwick

One such alliance is with the [Haematology Nurses and Healthcare Professionals Group \(HNNHCP\)](#). I recently returned from their conference, held in Zurich, where LC was given the opportunity to present lessons learned from the [Global Patient Survey on Lymphomas and CLL](#). On top of discussing medical issues, we used the conference to encourage nurses to think about how a patient's wellbeing is affected by the disease, including the long-term impact of fatigue, the high number of patients who experience changes to their key relationships and ongoing fear of relapse. Natalie Dren presented the research on the informed vs. uninformed patient, highlighting how nurses can play an important role in ensuring patients have adequate information and encouraging them to connect with, and refer patients to, their local patient organisations. Guy Bouguet shared his personal experience with lymphoma, as well as explaining how [France Lymphome Espoir](#) came to be and how it supports patients. The conference organisers themselves highlighted, when introducing the LC session, the importance of partnering with patient organisations and stressed the high-quality work that patient organisations do. There were many good conversations with nurses about the presentations. If anyone has any questions about HNNHCP in general or the conference, please [email me](#). As a reminder, by being a member of the LC, you are also a member of HNNHCP.

RESEARCH NEWS

- Axicabtagene Ciloleuceel in the Real World: Outcomes and Predictors of Response, Resistance and Toxicity [READ MORE](#)
- Long-Term Clinical Benefit to Anti-CCR4 Mogamulizumab: Results from the Phase 3 Mavoric Study in Previously Treated Cutaneous T-Cell Lymphoma (CTCL) [READ MORE](#)
- A Randomized, Double-Blind Efficacy and Safety Study of PF-05280586 (a Potential Rituximab Biosimilar) Compared with Rituximab Reference Product (MabThera®) in Subjects with Previously Untreated CD20-Positive, Low Tumor Burden Follicular Lymphoma (LTB-FL) [READ MORE](#)
- Molecular High-Grade B-Cell Lymphoma: Defining a Poor-Risk Group That Requires Different Approaches to Therapy [READ MORE](#)
- Patient Selection for CAR-T Therapy in NHL [READ MORE](#)
- Association of Health Behaviors and Quality of Life in Lymphoma Survivors [READ MORE](#)

There has been a lot of interest regarding the next global summit. The information is currently being finalised and will be distributed soon, but the meeting will be held in Spain the beginning of October. It will follow a similar format to the 2018 event, being a 2-day meeting with the second day including industry representatives.

For those that sent messages to Karen Van Rassel, recounting memories, thanking her for her support over the years, and wishing her well in retirement, I want to assure you they were all shared with Karen who was overwhelmed by your kind words. Karen and I have had many conversations through this transition and I appreciate her support and encouragement. I know she is wishing us all continued success.

I hope 2019 is a year of good fortune for all.

Lorna

LYFE APP: NEW FEATURE



LC recently released a new update to the Lyfe App. Chats in the **Community Section** can now be translated into 4 different languages:

- English
- French
- German
- Spanish

Learn more about the Lyfe App [HERE](#).

COMING SOON

The following tools are in progress and will be available in the first quarter of 2019:

- Genetic Markers Report
- Hodgkin Lymphoma GPS Report
- DLBCL Subtype Report
- Follicular Lymphoma Subtype Report
- CAR-T Toolkit

ASIA PACIFIC



Dear Members,

Welcome to the New Year and wishing best wishes to everyone for 2019.

I know many people had some time off over the holiday period so hoping that time was enjoyed with family and friends.

We look forward to reconnecting with you all in the coming weeks and updating on Lymphoma Coalition plans and updates.

Of note, a recent new approval of a new medicine developed in China - Tyvyt, for Hodgkin's Lymphoma Sintilimab - a fully human anti-PD-1 therapeutic monoclonal antibody. It was co-discovered by Innovent and Adimab and jointly developed by Innovent and Eli Lilly in China. [READ MORE HERE.](#)

Pru

EUROPE



On behalf of LCE, we hope you have a happy and fulfilling 2019.

Having set the ball rolling in 2018, there are two major LCE projects soon to come to fruition, as follows:

- **Cutaneous Lymphoma *Spreading the Word* project** – as part of ensuring the availability of clear, high quality patient information on this rare and often misunderstood lymphoma subtype, we have been working with the international, USA-based Cutaneous Lymphoma Foundation (and with support from the UK's Lymphoma Action) to develop an abridged version of the Foundation's Patient's

LCE IS PROUD OF ITS MEMBERS



Kraujas promotes a fractal drawing session for patients

A fractal drawing method is a way of helping a person

Guide. We have also adapted the guide for a European context (eg.including reference to the ESMO 2018 guidelines on cutaneous lymphoma) and are currently translating it into 30 European languages. These translated versions will be available shortly for review and amendment by member organisations in the individual countries, so that they can be checked for translation accuracy and for the inclusion of local information. We plan to complete the project in February 2019 and hope this will be a major contribution to meeting the information needs of cutaneous lymphoma patients throughout Europe.

- **Lymphoma and CLL Community Advisory Board (CAB)** – many of you will have seen the information we circulated last year on the Lymphoma/CLL CAB that we are setting up in partnership with EURORDIS Rare Diseases Europe. We have been really pleased with the first round of recruitment for CAB members – more than 15 people applied, and we hope to add to this number with further applications in the second round which is currently in progress. We are in the process of responding to all the applications with the aim of holding our first CAB meeting in Brussels, Belgium, from 1 to 4 April. All being well, further meetings will be held in the first week of July and early November.

For further information on either of these projects or to get involved, please contact either [Jonathan](#) or [Natacha](#).

LCE IS PROUD OF ITS MEMBERS



Hematon helps create a treatment decision aid for CLL patients

CLL patients perhaps never had the feeling that they had a choice regarding their treatment. Considering this challenge, Hematon together with the PATIENT + office and haematologists are developing a decision

to live creatively, a form of art therapy. It does not have the purpose of creating artistic masterpieces, although practitioners create truly impressive works. Creating fractals aims to impact the well-being of patients, as it helps with self-expression. [LEARN MORE](#)

New brochures for Slovak patients with Hodgkin lymphoma

Slovak patients newly diagnosed with Hodgkin lymphoma will receive a new treatment brochure from their haematologists. The brochure, produced by Lymfoma Slovensko in cooperation with National Oncology Institute in Bratislava - a member of the Slovak Lymphoma Group - will be distributed to all treatment centres in Slovakia. [READ MORE](#)

NEWS FROM EUROPE

Patients will speak at the 1st European CAR T-Cell Meeting

The recent approval of the first CAR T-cell treatments in Europe has revolutionised the treatment landscape for patients with advanced lymphoid malignancies, but also poses challenges regarding patient access, handling of specific toxicities, organising treatment units and coping with the increasing costs connected with the therapy. With this in mind, the European Hematology Association (EHA) and the European Society for Blood and Marrow Transplantation (EBMT) jointly organised this medical meeting - the

tool, intended for people with CLL who can not tolerate heavy chemotherapy. The decision aid will help patients and haematologists conduct conversations about the choice of treatments and whether or not to treat the disease. Patients will be involved in the development of the tool, bring their perspective on considerations - concerns, preferences, expectations - that play a part in making a choice. The importance of information about survival, effectiveness and side effects will also be discussed. [READ MORE](#)

Mission - movie about the Hungarian Cancer League

The [50-minute film](#) presents the work of the volunteers of the Hungarian Cancer League. The film was designed by Éva Wortmann, a volunteer who had dreamed of making a film about the Hungarian Anti-Cancer League for three years. [READ MORE](#)

Bulgarian Lymphoma Patients' Association "Innovation for Life" Campaign

The Bulgarian Lymphoma Association (together with Bulgarian Medical Association of Hematology, Bulgarian Medical Society for Child Hematology and Oncology and ARPharM Association of Bulgarian Pharmaceutical Manufacturers) created a campaign to show that life with blood cancer is possible; sending a strong message that innovative therapies are necessary and additional investments are needed. The initiative aimed to raise awareness of blood cancers and modern diagnosis and treatment options, as well as the problems patients face. As part of the activities there was a round table at the Parliament under the patronage of the Parliamentary Healthcare Committee. [READ MORE](#)

first of its kind in Europe. [Lymphoma Coalition](#) (N. Bolanos) and [Hematon](#) (B. Verhoeven) have been invited to speak and address issues that are relevant to patients. The conclusions will be shared after the meeting.

Lymphoma Coalition is providing a coordinating role to the recently launched T-Cell Lymphoma Consortium, aimed to lead the research within the Harmony Consortium. A bench-to-bedside research proposal on peripheral T-cell lymphomas (PTCL) is currently being reviewed by the different working groups of the consortium, including ethical review. Patients with PTCL have a poor treatment outcome with 1/3 primary refractory cases and 1/3 of patients relapsing in the course of the disease. Prognosis in relapsed or refractory setting is devastatingly poor. Histopathological diagnosis of PTCL sub-entities is challenging and the prognosis is very heterogeneous even within these defined sub-entities.

Within the PTCL HARMONY study, we expect to evaluate the impact of omic data on defining clinical relevant subclasses, prognostic, predictive subcategories in a large scale dataset. Moreover, we want to develop and implement a harmonised diagnostic and prognostic consensus sequencing panel for PTCL. Datasets from international, national and institutional clinical registries will be integrated with clinical trials. This project will help guide clinical treatment decisions, the development of new treatments in PTCL, and improve overall survival rates.

