

## Our Mission

**LYMPHOMA COALITION**

Worldwide network of 69 lymphoma patient organisations from 45 countries acting as a central hub for reliable and current information.



Be the global source for lymphoma facts and statistics



Improve awareness and understanding of lymphomas



Build capacity for new and existing lymphoma groups

Dear Lymphoma Coalition Member,

Lymphoma research is exploding and it is important that we keep up to date on what is being put forward with an eye on patient outcomes, safety and side effects both short term and long term. Lymphoma Coalition strongly believes in the involvement of patient groups from the beginning of trial design and research projects so we may influence acceptable patient outcomes at the inception. Find a way to get involved in this process.

As part of LC capacity building to ensure all members are on a level playing field of information, we continue to report by subtype. The latest report on Marginal Zone Lymphoma, highlights the lack of direct therapeutic support. As a rare lymphoma, more attention and research is required to understand the biology and hence develop targeted therapies. Read [more](#).

KnowYour Subtype 1.5 messaging has begun and will continue through to World Lymphoma Awareness Day. Social media messaging has been created using the 3 pillars of the campaign (Empower Patients, Report by Subtype and Global Impact). The posts along with the suggested links/graphics are part of the online toolkit in the member section of the website. Also being created for your use is a new media advisory for dissemination/posting and an updated landing page designed for you to use on your websites. Let's keep the conversation going.

The WLAD member committee will be presented with the concepts for 2017 by OpenCo for the traditional media campaign and by Social Media 101 for the social media campaign by the first week of April.

It is our commitment to ensure that it is all completed and a member's toolkit sent to you by the end of April.

Congratulations to Charlotte and team for a well-run Lymphoma Coalition Europe members meeting that was held in Madrid on March 13 & 14th. The focus was on capacity building in two areas; working with HTA bodies as well as on Communication planning and how to use multiple platforms. Charlotte has gone into more detail in her report below.

Please mark your calendar for the 15 year celebration of Lymphoma Coalition at the 2017 Global Summit that will be held on December 7 & 8, pre ASH in Atlanta, Georgia USA. More details will be sent to you next month.

I wish you great success in your upcoming fundraising efforts and your patient education projects.

Warmest Wishes,

Karen.

### COMPARISON OF PHARMACEUTICAL, PSYCHOLOGICAL, AND EXERCISE TREATMENTS FOR CANCER-RELATED FATIGUE

This article outlines the steps taken to compare and answer-Which of the 4 most commonly recommended treatments for cancer-related-fatigue—exercise, psychological, the combination of exercise and psychological, and pharmaceutical—is the most effective?

Read more [here](#).

### RISK-BASED THERAPY FOR DLBCL

As part of the Onclive Peer Exchange, this video is a panel discussion weighing in on emerging concepts for the treatment of aggressive lymphomas.

Read more [here](#).

### EC APPROVES TOPICAL CHLORMETHINE GEL TO TREAT MF-TYPE CTCL

This summary explains how the Agency assessed the medicine to recommend its authorisation in the EU and its conditions of use. This topical, once-daily and colorless gel is used as a treatment for MF-CTCL a common form of cutaneous T-cell lymphoma.

Read more [here](#).

### CLINICAL APPLICATIONS OF THE GENOMIC LANDSCAPE OF AGGRESSIVE NON-HODGKIN LYMPHOMA

Genomic technologies, including microarrays and next-generation sequencing, have enabled a better understanding of the molecular underpinnings of these cancers.

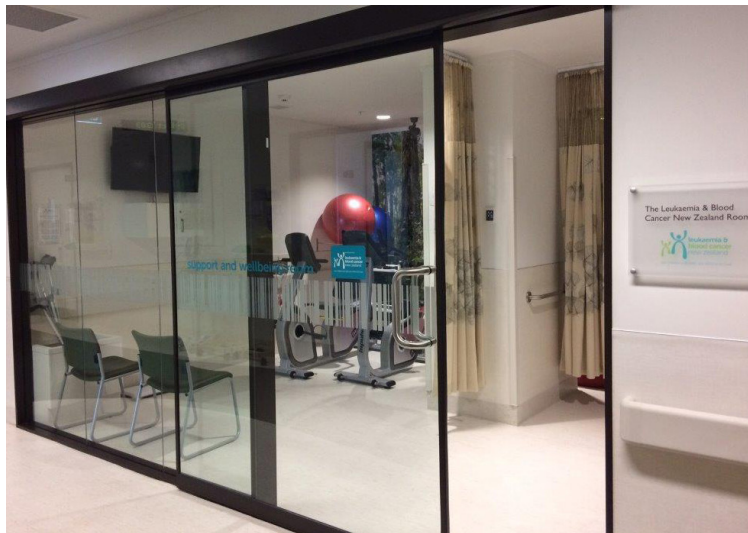
Read more [here](#).



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## LBC's Approach to Optimising Support for Patients with a Blood Cancer



The patient experience when dealing with a blood cancer can be a time of great psychosocial upheaval, something that is well understood by Leukaemia & Blood Cancer (LBC) New Zealand. This is evidenced by LBC's patient support services team of seven people who meet with patients around the country, and who are based within the major regional oncology and haematology treatment centres in New Zealand; namely, Auckland, Christchurch, Hamilton and Wellington.

"The rationale for having staff based in the same locations as the major treatment centres is mostly because of the dispersed population. As well, very often patients and their caregivers have to relocate for treatment which is often very traumatic," said Pru Etcheverry, the Chief Executive Officer of LBC.

"LBC's patient support team provides patients with support in whatever form that needs to be," she said. All members of LBC's patient support team are either haematology- or oncology-trained registered nurses although, on occasion, some have had a psychology or social work background.

Patients may contact LBC on their hotline to better understand their diagnosis, treatment or the role of clinical trials.

"Where the rubber hits the road, though, is around the psychosocial aspects such as worries about their family falling apart, financial implications like putting food on the table, employment and so on," said Pru.

Patients also need support while in hospital undergoing treatment. To help with this, LBC undertook to sponsor the Support and Wellbeing Room in the Motutapu Ward at the Auckland City Hospital. This room is part of the Northern Regional Haematology and Bone Marrow Transplant Ward which opened in 2014.

"This LBC-branded room sits in the heart of the ward," said Pru.

After lengthy consultations LBC had with the nurses and other members of the clinical care team, including physiotherapists and occupational therapists, it was determined that the room would have some physiotherapy as well as occupational therapy equipment.

"We also negotiated having a member of LBC's patient support team present in the room one half-day every week. While LBC has good access to the ward and is well respected, it is still hard to always be top of mind and get patients referred to LBC services," she said.

Having a presence on the Motutapu Ward did result in an increase in the number of referrals of patients who were newly diagnosed in Northern Region of New Zealand to LBC: in 2014 referrals/self-referrals to LBC were 46.3%; in 2016 they were 57.4%.

Read more [here](#)



### SUBTYPE REPORT SURVEY UPDATE

Thank you to the 34 member groups who completed the Subtype Report survey. The feedback received was very helpful in directing the future path of the Subtype Reports. The results and proposed next steps will be presented and discussed at the LC Board Strategic Planning in April. We will provide you with a detailed report shortly following the meeting.



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Dear Members,

It is difficult to summarize the rich content and outcomes of the 2017 Lymphoma Coalition Europe members' meeting that recently took place in Madrid on March 13 and 14th. There were 29 representatives of lymphoma and CLL patient organisations from 21 European countries. The focus of the meeting was on capacity building in Digital Communications Planning and Execution and Working with HTA Bodies. The few pictures displayed in the newsletter will give you an idea of the robust atmosphere of both sessions.



“Digital first” was the main message of the communication session, which was videotaped and will soon be available in the member section of LC website together with all the meeting presentations and [pictures](#). Denise Harkin and Jenny Coldwell from the Lymphoma Association, coordinated the session on communication and trained us well in how to move forward with our communication strategies. Thank you to Biba (Borka) and Villy (LYLE) for their best practice illustration on main stream media and digital marketing.

Seven healthcare professionals (hematologists, nurses, health psychologists, etc.) and researchers and I I industry representatives attended the meeting on March 13, and discussed with LCE members, both in presentation format and roundtable discussions, how to better inform and support patients in Europe. The panel and round table discussions evidenced a lack of mutual knowledge and trust between physicians and patient organisations, as well as a lack of cooperation among the different actors in the creation and the delivery of patient information. The solutions and recommendations to improve collaboration among patient organisations, HCPs and the pharma companies that came out of the discussion are available in the member section of LC website, and will be used as a basis for the further development of LCE capacity-building plans and partnership strategies.

The session on Health Technology Assessment (HTA) was another highlight of the meeting. [Jean-Pierre Thierry's](#) presentation helped us understand how HTA works in Europe, and how it evolved over time to include the patient perspective. This was then illustrated by Natacha (AEAL) and Guy (FLE), who shared their experience of participation in the evaluation of medicines respectively in Spain and in France. The dialogue with Jorge Camarero and Laura Oliveira from the Spanish Medicines Agency was also very useful to understand the regulator's point of view on patient involvement.

LCE would like to thank all of you for sharing amazing good practices, creating unique videos, expertly moderating the workshops and contributing to the lively group discussions with thoughtful inputs. A special token of gratitude goes to Denise Harkin and Jenny Coldwell from the Lymphoma Association, who coordinated the session on communication with such professionalism. The active participation of all members made this meeting special.

Mark your calendars for the EHA Congress that will take place from June 22 to June 25 in Madrid. LCE will have a booth in the exhibition hall, and we will take advantage of this opportunity to further liaise with HCPs from all over Europe. We encourage you to reach out to your local supporters as soon as possible, and ask them to support your participation in the Congress as it is a great occasion for knowledge development on the latest research in lymphomas. In the meantime, plan to send your materials to the congress centre, attention to my name and the LC booth and we will display your patient materials.

Charlotte



## EDUCATION SESSIONS - APRIL 2017

### USA – Rocky Mountain Blood Cancer Conference

04/08/2017

[Click here](#) for details.

### Germany - Lecture: Will-making and Inheritance

04/27/2017

[Click here](#) for details.

### Canada - CLF Patient Educational Forum

04/29/2017

[Click here](#) for details.

For a full listing of events around the world, see the [event calendar](#) on the website. Let us know about your upcoming education programmes so we can promote them.



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