

Our Mission

LYMPHOMA COALITION

Worldwide network of 66 lymphoma patient organisations from 44 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 Coalition Member,

It has been a year of extensive activity in the lymphoma world. With many research projects and clinical trials underway, as well as many applications for approvals at the regulatory level for both combination and newer molecules, there is a lot to share with your patient communities.

The LC subtype reports are well written and strictly for this purpose. They help us understand what is going on by subtype and to get an understanding of the patient experience that goes hand in hand with therapy access and clinical trial availability.

To date you can read about DLBCL, FL, CLL, HL, WM and a specific CLL report for Europe, and next month we will add the updated MCL report. You are welcome to use them in any capacity, we just ask that you reference the LC material by report title. Here is the [link](#) for your reference.

The email for the **Annual General Meeting** was sent to you this month. Please review it and let me know if you have any concerns or questions. A link to a [survey](#) was sent in that email with a request for you to please take 5 minutes and complete it so we may gather information on your understanding of **Pharmacoeconomics** to assist us in our capacity building efforts with you.

For those attending the Global Summit you would have received the **Global Summit confirmation email** from Kim. Let her know if there are any details that need to be corrected.

We look forward to seeing you in San Diego, at the lovely Horton Grand Hotel, November 29 - December 1.

Bring your cowboy/girl boots or a close likeness!

Warmest Regards,

Karen



Subtype Review Diffuse Large B-Cell Lymphoma

The focus for this report is to review diffuse large b-cell lymphoma (DLBCL) to determine therapy access, clinical trial availability, incidence and mortality, and some aspects of the patient experience.

View the report [here](#).

CLL: AN ACQUIRED IMMUNODEFICIENCY DISEASE

The effects of BCR pathway inhibitors on immune function and the risk of infection in patients with CLL need further study to provide the data required to optimize management with this important class of drugs...

Read more [here](#).

HSP90 INHIBITION OVERCOMES IBRUTINIB RESISTANCE IN MCL

The BTK inhibitor ibrutinib induces responses in 70% of patients with relapsed and refractory mantle cell lymphoma.

Read more [here](#).

CAN CELL OF ORIGIN INFORM MANAGEMENT OF DLBCL?

Studies have found that patients with each of these types of disease respond to the same therapies differently, and have differing survival outcomes.

Read more [here](#).

Leukemia & Lymphoma Foundation

(Singapore)

The impetus for the founding of the Leukemia & Lymphoma Foundation (LLF), in Singapore in 2002, was the need to provide financial assistance to needy patients who had found a suitable donor match for stem cell/bone marrow transplantation.

“At that time, there was a bone marrow registry in Singapore but the majority of the donors were sourced from outside of the country. The cost of procurement was high and beyond the means of many patients. Our focus now is on helping patients pay for the cost of undergoing a stem cell transplant (SCT) along with other expenses patients may need assistance with,” said Dr. Lydia Seong, Chief Executive Officer of LLF. Lydia is a medical doctor whose specialty is public health.

Lydia is one of the founding members of LLF. In her day-to-day work for LLF, she is supported by one other staff member and volunteers who help with LLF’s administrative needs. LLF has a board that is responsible for approving all funding applications made on behalf of patients requiring financial assistance.

“On average, we help between 30 and 40 patients in a given year,” she said. In previous years, LLF assisted more than 80 patients a year but with the availability of other financing schemes, over the last four years financial assistance has stabilised to helping 30 to 40 patients in a given year.

白血病与淋巴瘤基金会

COALITION EVENT REMINDERS

LC Global Summit

November 30 - December 1, 2016

Location: San Diego, California, USA

American Society of Hematology (ASH) Annual Meeting

December 3-6, 2016

Location: San Diego, California, USA

LLF’s primary objective is to raise funds to support the financial assistance given to patients.

“Our second objective is to support families. Most patients go through a very long treatment journey and families can be neglected as a result,” said Lydia. The support provided to families is primarily emotional.

LLF’s other objectives are research and education.

“However, research is not very high on our agenda as hospitals already have research grants and other funding sources for research,” she said.

LLF does undertake initiatives to help raise awareness among the public about blood cancers.

Read more [here](#).

STANDARD OF CARE FOR DLBCL AND DOUBLE-HIT LYMPHOMA



Laurie Sehn, MD

British Columbia Cancer Agency, Vancouver, Canada

0:12 / 1:33

Laurie Sehn, MD of British Columbia Cancer Agency, Vancouver, Canada discusses the standard of care for patients with diffuse large B-cell lymphoma (DLBCL).

[Watch the video here.](#)

PTCL - RANDOMIZED TRIAL WITH MOGAMULIZUMAB



Gilles Salles describes the R/R ATL trial, a randomised trial with Mogamulizumab for patients with PTCL.

[Watch the video here.](#)



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lymphomacoalition.org
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Dear Members,

October is always a busy period and this one was no exception for LCE. We started with ESMO (European Society of Medical Oncology) annual conference, which took place in Copenhagen (again!) from 7 to 11 October.

LCE shared a booth with MDS Alliance represented by Anita, who helped us inform the Congress participants about LC / LCE and [#knowyoursubtype](#) campaign.

Thank you Anita! We handed out two new communication tools – the [#knowyoursubtype](#) bracelets and LC leaflets – that were both very helpful to raise participants' awareness about who we are and what we do.

The Congress was very well attended by patient organisations – around 150 cancer patient advocates were registered, including 7 representatives of LCE member organisations – and proved to be a great opportunity of knowledge building and networking. While the ESMO scientific and educational sessions specifically dedicated to lymphomas were just two, the panels included prominent experts of different subtypes presenting the new therapeutic strategies in a didactic and accessible manner (see the session reports on [Lymphoma Hub](#)).

The [patient advocacy track](#) was the largest congress track, with many hot topics and excellent speakers. The audience exceeded the capacity of most session rooms, and oncologists represented a large share of the public. Together, with this new concept of the patient advocacy track, ESMO decided to consider patient advocates as part of their membership and to welcome them for a symbolic [fee](#). The 2017 ESMO Congress will take place in Madrid from 8 to 12 September, and I thus encourage all of you to attend next year.

LCE is updating the CLL European report with current information on patient experience and access to treatments from the LC 2016 Global survey and Global database. This information will be presented on 12 November in Belgrade, Serbia, in occasion of the CLL Horizons meeting that some of you shall attend. The report will also be available on the LC website in the middle of November.

I had the fabulous opportunity to interview most LCE members, and we now have about 30 completed questionnaires out of 35 registered member organisations, which is an excellent result. I heartily thank you for the time you dedicated to answer my many questions, which helped me know you better. The results of this survey have been compiled so we can analyse the main issues experienced by lymphoma patient groups and patients around Europe, as well as your expectations vis-à-vis LCE. We will make good use of this information to inform LCE strategy and planning for the coming years.

Finally, you will soon receive an official confirmation of the date and place of LCE next members meeting. Spring and Spain shall be the key words...

Best wishes,

Charlotte



EDUCATION SESSIONS - NOVEMBER 2016

**Chronic Lymphocytic Leukaemia
(CLL/SLL) Teleconference**

11/03/2016

Click [here](#) for details.

**Blood Cancer Awareness Week
New Zealand**

11/07/2016 - 11/13/2016

Click [here](#) for details.

LC Global Summit

San Diego, USA

11/30/2016 - 12/11/2016

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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