



Dear LC Members,

Many of you have responded to the 15th annual LC Global Summit invitation in Prague on 6 & 7 July (in place of the typical December meeting), so it should be quite successful in terms of sharing best practice. For those that have not responded to date, it is not too late to submit your registration forms to [Kim](#).

The Global Summit will be unique as we include Regional Breakouts along with the Global activity. It was felt that the joint global and regional meeting would help to save members' time and dollars by holding one meeting a year as we grow in size and begin to develop the regions and their activities. We can then ensure that we remain a global body while working regionally and locally.

The goal for this meeting is to ensure member organisations understand the significance of combination therapies and why they are combined, as well as to support the sustainability of organisations.

Highlights include:

- Jeff Boss will address the full global body on **Removing Roadblocks** on the first day. Check out his website [Chaos Advantage](#). A sought-after speaker on leadership, mindset, and high-performance teams, Jeff also writes weekly for [Forbes](#) and [Entrepreneur](#). You won't want to miss this.
- The **LC Europe** breakouts will focus on capacity building around access and taking next steps towards the Lymphoma Community Advisory Board (LCAB) based on the EURODIS model of patient experts in a particular disease area who offer their expertise to public or private sponsors of research, often in conjunction with a small group of clinicians.
- **LC Asia Pacific** will launch its region at the Summit and will focus on mapping out the regional needs along with hearing from Jeff Boss on leadership.
- The **rest of the world** will focus on leadership development with guest speaker Jeff Boss, as well as learn new ways to share best practice on clinical patient experiences to add to the approval requirements at country level.

The **AGM** will be held on the first day over lunch and you will be called upon to approve a number of items. The agenda will be sent out early in May.

The Global Patient Survey results will be available soon and we are working on some new technology that might be helpful in allowing you to pull data in a number of different ways. Stay tuned for more information.

Don't forget to let [Karen Royds](#) know if you have any educational sessions coming up and we will add it to the LC calendar.

Warm regards,

Karen

## STANDARDS OF EXCELLENCE PROGRAM



If you believe your organisation fulfils the criteria for one or all of the [Standards of Excellence Program](#) badges, you can complete the online submission, upload the supporting documents and earn a badge.

The next quarterly review date for submissions is **31 May 2018**. If you require assistance with completing this work, please email [Karen](#).

## MEMBER SPOTLIGHT

**Blodkreftforeningen, Norway**



Blodkreftforeningen (Norwegian Blood Cancer Association) is focused on creating an organisation that is responsive to patient and carer need. It currently has 7 locations, over 1500 members across Norway, and offers a variety of educational and support programs. Find out more about their important work [HERE](#).

## RESEARCH

- NIH study revises molecular classification for most common type of lymphoma, DLBCL [READ MORE](#)
- Overall survival benefit in patients with rituximab-refractory indolent non-Hodgkin lymphoma who received obinutuzumab plus bendamustine induction and obinutuzumab maintenance in the GADOLIN study [READ MORE](#)
- EBMT 2018 | Cord blood NK-CAR therapy may be an alternative to CAR-T in the treatment of lymphoma [READ MORE](#)
- Prognostic value of baseline metabolic tumor volume in early-stage Hodgkin lymphoma in the standard arm of the H10 trial [READ MORE](#)
- Balancing risk and benefit in early-stage classical Hodgkin lymphoma [READ MORE](#)

## LEARNING EXCHANGE WEBINAR SERIES

LC has introduced the **Learning Exchange Webinar Series**. For the first webinar, Susan Thornton, President of the Cutaneous Lymphoma Foundation and Chair of the LC Board, and Dr. Pierluigi Porcu, a leading expert from the Sidney Kimmel Cancer Center in Philadelphia, discussed **cutaneous lymphomas**. Thank you to our exceptional speakers and the participants who were able to join. The webinar is available [HERE](#).

## WHATS APP



LC is forming member WhatsApp groups to diversify ways we can communicate with each other. If you would like to be part of these groups, please share the name, what area they may be responsible for (such as communication) and phone number of the people within your organisation who should be included. Email the information [HERE](#).



Pru Etcheverry started as the LCAP Regional Director this week. She is already busy learning as much as she can about the LCAP member organisations. If you wish to contact Pru, she can be reached at [pru@lymphomacoalition.org](mailto:pru@lymphomacoalition.org).

## LCE NEWS



The LCE plan for 2018 and beyond includes some exciting new projects which will be shared in more detail over the coming months and at the Regional Summit in Prague in July.

LCE wants to involve member organisations as much as possible in current work and future plans, which is why the Advisory Committee is being renewed and expanded. Hopefully you have seen the email messages that went out about joining the committee. Thank you to those who have already expressed an interest. It's still not too late to join. Please contact [Natacha](#) or [me](#) if you are interested.

In a similar vein, a survey was circulated to all LCE members about current priorities and needs in your country/organisation, as well as views on LCE's work and future projects. A good number of responses have been received, which is appreciated, and it would be great to have some more. The survey can be accessed [here](#).

Finally, Natacha and I will be attending the EHA Congress on 14-17 June in Stockholm. If you're planning to be there, please let us know so that we can arrange to meet up. If you won't be at EHA, then hopefully we will see you at the Summit in Prague.

Jonathan

### LCE MEMBER INFORMATION SURVEY

As part of its advocacy strategy, the LCE is gathering information about European member organisations, with the objective of gaining an overview of key issues in each country so that the potential next steps can be better identified and individual organisations supported where needed.

[TAKE SURVEY](#)

## LCE is Proud of its Members



Flute of Light (Israel) published an updated list of new hemato-oncology drugs that are funded in Israel by public insurance, to ensure patients and carer have information on these innovative treatments. Six new treatments were included that benefit lymphoma patients. The list contains the generic and commercial name of the new medicine, indication, number of patients who're receiving the treatment and the cost in NIS millions for the healthcare system. The 'health basket' encompasses the entire range of services, drugs, medical equipment and devices that the insured public has a right to receive. The list of medications included in the basket is closed and updated every year. Any public or private entity (i.e. patients, patient organisations, doctors, companies, etc.) may submit a request to add new medications to the healthcare services basket. [READ MORE](#)

 Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström (SILLC), in English the Association of Support and Information for Chronic Lymphocytic Leukaemia (CLL) and Waldenstrom's Macroglobulinemia (WM) published "My Care Pathway", a 154-page report providing the results of their survey of over 900 patients. The report lists 20 recommendations that SILLC is bringing to the attention of healthcare professionals; as well as guidance for improving patient care in the medium-term for the French health system, considering the changes currently in progress. This report focuses on the organisation of care, quality of care and the level of communication required to optimise treatment and quality of life. [READ MORE](#)

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**Leukaemia Care** YOUR Blood Cancer Charity It is estimated that there are currently around 13,300 Chronic Lymphocytic Leukaemia (CLL) patients living on Watch and Wait in the UK instead of being treated. The length of time a patient is on Watch and Wait before requiring treatment is a significant uncertainty. For many patients there is a substantial emotional and physical burden that comes with watching and waiting, or rather, worrying. Leukaemia Care reveals, in its last report, that over half of CLL patients on Watch and Wait report feeling more depressed or anxious following diagnosis. However, there is a significant lack in provision of both information and support to help these patients come to terms with their diagnosis and adjust to living with an incurable cancer. Therefore, a new guidance document for patients has been launched, *Living Well with Watch and Wait*. This guide uses the experience of CLL patients to provide with helpful advice and point towards the resources that can help patients during your CLL journey.

Download the 'Watch and Wait Worry' report and 'Living Well with Watch and Wait' [HERE](#)

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Returning to work can be tricky, and support may not be available after cancer treatment ends. The purpose of the **me, cancer and work project**, created by Suomen Syöpäpotilaat ry (Finland), is to facilitate the return of people who can work to the workforce by providing physical, psychological and social support. The project is implemented in person in the Uusimaa, Pirkanmaa and North Karelia regions. Patients in other areas can participate online (via chat, Google Hangouts, etc.). Individual and group counselling is provided for those who need support. At the same

time, information is provided about the importance of maintaining the working life skills of a cancer patient during treatment and rehabilitation. An additional goal of the program is to deepen cooperation between cancer organisations and provide information on public sector employment services and occupational healthcare needs. [READ MORE](#)

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## NEWS FROM EUROPE



Radiation Oncology is an innovative discipline which is rapidly evolving, and radiation therapy (RT) is an important component of the management of lymphoma patients. The primary treatment of Hodgkin lymphoma (HL) and other aggressive lymphomas is often a combination of systemic treatment and local RT, and in many localized indolent lymphomas, RT is the sole primary treatment. RT also plays an important role in the treatment of relapsed or refractory disease and palliative treatment of lymphomas. Modern techniques have increased the precision of RT, and have made it possible to reduce dramatically the risks of long-term side effects while maintaining treatment benefit.

In order to find up-to-date knowledge on RT, LCE is engaging with [ESTRO](#), the European Society for Radiotherapy & Oncology. LCE attended ESTRO 2018 in Barcelona in April for a one-day clinical joint ESTRO-[ILROG](#) (International Lymphoma Radiation Oncology Group) course on radiation for lymphoma. This highly informative day gave an update on the evolving role of radiation therapy in malignant lymphoma. The presentation covered new guidelines and technologies as well as the integration of radiotherapy with new regimens, particularly immunotherapies. This information is going to be shared with members in the next month.

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