

## 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,

We are halfway through the year already and so many of you have accomplished so much in such a short period of time. Congratulations.

The Global Patient Survey and the 15 local reports will be distributed over the next few weeks. This information is valuable to use in press material, advocacy material, and on your websites to bring attention to the patient experience in lymphoma.

The 2016 LeP Report Card will focus on the patient experience and unmet needs coming out of this report, comparing it to the information from the Global database.

The LC Europe members meeting June 8 in Copenhagen is almost here. We wish you an excellent meeting.

As you know, planning for the Global Summit in San Diego, November 29-December 1, is well underway. The location for the meeting, the Horton Grand Hotel, is nicely situated in the heart of San Diego. We are working on topping the Whirly Dome for our team-building activity. Not sure this is even possible!

We're looking forward to seeing you there so please block this time and plan on attending.

Warmest Regards,

Karen

June is **Acute Myeloid Leukemia Awareness Month**. Acute Myeloid Leukemia (AML) is a cancer of the blood and bone marrow.

Many of you support this patient cohort so we wanted to remind you of it. CancerCare is leading a national awareness campaign to bring more attention to AML.

They are also partnering with **NBA broadcaster Craig Sager** (himself diagnosed with AML) and his family to help spread the word. Consider posting a mention of AML Awareness Month on your website and in your communications with your constituents.

Below are some links to content as well as a link to a video vignette featuring Craig and his family.

**AML Awareness Webpage:**

<http://www.cancercare.org/amlaware>



### WHO REVISED LYMPHOID NEOPLASM CLASSIFICATION

The World Health Organisation (WHO), has revised the classifications for lymphoid Neoplasms.

Read more [here](#).

### SMALL-MOLECULE TARGETED ANTICANCER DRUGS

Are doses and schedules of small-molecule targeted anticancer drugs recommended by phase I studies realistic?

Read more [here](#).

### THE SPECTRUM OF MALT LYMPHOMA AT DIFFERENT SITES

The biological and therapeutic relevance of MALT lymphoma is evaluated at different sites.

Read more [here](#).



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## Patientforeningen for Lymfekræft og Leukæmi (LyLe), Denmark

A patient group focusing on lymphoma and leukaemia was the start of Patientforeningen for Lymfekræft og Leukæmi (LyLe) in Denmark.

“There were no specific support groups for patients with lymphoma or leukaemia and it was seen as being very important to have somewhere for these patients to go to get support and information for their particular needs,” said Rita Christensen, the president and chair of LyLe.

LyLe was formed in September 2007 and Rita got involved as a volunteer in November 2007.

“I discovered LyLe on the internet. I had written a book about my experiences with chronic myelogenous leukaemia (CML) and I wanted to donate the profits from the book to an organisation. When I read about LyLe, I decided I had to work for them,” she said.

In 2008, Rita was elected to the board of directors and at the end of 2013, she became the president and chair of LyLe.

### Evolution of LyLe

Since its inception, LyLe has changed in many ways.

“When LyLe first started, everything we did was for all haematological diseases. When I became president and chair, I decided it was very important for patients to get information about their own disease rather than information about all haematological diseases,” Rita said.

Today, LyLe has annual events that focus specifically on the different haematological diseases it supports; namely, acute myeloid leukaemia, acute lymphocytic leukaemia, chronic lymphocytic leukaemia, CML and myelodysplastic syndrome. This also supports LyLe’s main objective.

“Our main objective is to provide information about the different cancers we support. We have a magazine, called *LyLe Focus*, which focuses on the different types and that also helps us achieve this objective,” she said.

Another objective is to meet the different needs of members.

“Some members want to meet other people in person, others want to meet through Facebook, and a third group only wants to write or chat. So, we have expanded our reach with Facebook, Twitter, YouTube and Instagram,” she said.

### Challenges Facing Danish Patients

Until now, a big challenge facing patients in Denmark was obtaining disease information.

“There wasn’t a lot of information available about leukaemia and lymphoma but, with the services LyLe provides and the purchase of the Blood Cancer DK website, everyone can find us,” Rita said.

Another challenge facing patients is the cost and timeliness of treatment. The Danish government has unveiled a new plan—Cancer Plan IV—the objective of which is to ensure patients diagnosed with cancer receive treatment they need in a timely manner.

“Because of this new plan, we have many things to do to ensure our needs are expressed. We want patients to get access to current treatments and access them faster so they have a better chance of survival,” she said.

Before a treatment is approved for funding and reimbursement, it has to undergo a health technology assessment. This assessment is carried out by the Danish Health and Medicines Authority (DMHA), an organisation that is similar to National Institute for Health and Clinical Excellence (NICE) in England and Northern Ireland.

“DMHA wants to make similar changes as NICE has made and we are worried about this as we don’t want to lose the treatments we already have,” she said.

Obtaining needed rehabilitation is also an issue confronting patients. Patients in Denmark are entitled to receive rehabilitation. However, findings from a survey undertaken in 2015 indicated that 89% of respondents were not informed about this right. Also in 2015, a rehabilitation centre for cancer patients was closed for financial reasons.

“Rehabilitation has been outsourced in the communities where they are starting from scratch. These programmes are not meeting the demands or needs of patients. Our goal is to improve its availability,” she said.

LyLe is drawing attention to the issue through Facebook, Twitter and YouTube. In spite of these issues, Rita is satisfied with the healthcare provided in Denmark.

[Read more.](#)

## Keep Spreading the Word About the Importance of Knowing Your Subtype

By now we hope you’ve updated your websites with the banner and webpage found in the Know Your Subtype toolkit. Soon you’ll also receive a media kit, which will include a press release and an article that you can customize to send to your local media outlets to help build awareness around the need to know your subtype.

Next month we will also be sending the WLAD toolkit, which will heavily focus on Know Your Subtype and will include lots of great materials for your use as you plan local events for September 15. Stay tuned!



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Dear Members,

There are only a few days left before the LCE members' meeting and we are thrilled to meet many of you in Copenhagen on June 8. Thirty members representing 22 organisations from 18 EU and non-EU countries will attend the meeting, which is an exciting perspective.



For those who will attend the Congress of the European Hematology Association (EHA) from June 9-12 in Copenhagen, we have an excellent opportunity to participate in two events organised by our pharma partners. On **Thursday, June 9**, **Takeda** will organise a **breakfast meeting** focusing on patient engagement in clinical trials, during which you will have a chance to sit and discuss with your regional and local Takeda affiliates.

**On the same day, AbbVie** has invited LC to present the CLL patient experience in a stakeholder briefing looking at "What's on the horizon in CLL Management" from 1 – 2:30pm. Patient Relations Managers at country level will be attending, as well as the European press. If you would like to attend but did not receive the invitation to those events yet, please contact me, [charlotte@lymphomacoalition.org](mailto:charlotte@lymphomacoalition.org) right away.

During the EHA Congress, LCE will chair one of the Patient Advocacy sessions (Saturday, June 11, from 11:30- 12:45) dedicated to the implications of the new EU Clinical Trial Regulation for investigators and patients.

LCE is collaborating with the European CanCer Organisation (ECCO), which promotes the voice of cancer professionals in Europe. Since the beginning of the year, Jonathan Pearce has been a member of the ECCO Patient Advisory Committee on behalf of LCE. The objective of this Committee is to ensure that the patient perspective is reflected in all of ECCO's activities. Jonathan's active participation in the Committee's work contributes to including LCE's views in European policy issues of interest to lymphoma patients (e.g., the Roadmap for action on patient empowerment developed by the [European Patients' Forum](#) with ECCO's contribution).

At the next [ECCO Congress](#) (January 27-30 2017 in Amsterdam), Jonathan will chair the Patient Advocacy Track session dedicated to side effects.

LCE continues to facilitate the participation of lymphoma patients in the risk-benefit assessment of medicines by the European Medicines Agency (EMA). On May 18, Caroline Bushell (Lymphoma Association UK Advisory Group) participated in a [Scientific Advisory Group](#) meeting aimed at discussing safety concerns in relation to a medicine in the treatment of chronic lymphocytic leukaemia (CLL) and follicular lymphoma (FL). Like Guy Bouguet, Caroline appreciated the opportunity to voice her concerns and expectations as a patient.

This topic is one that will be good to discuss during the LCE members meeting with our guest speaker, Francesco Pignatti, Head of Oncology, Haematology and Diagnostics at the EMA.

I'm looking forward to seeing you in Copenhagen!

A handwritten signature in blue ink that reads 'Charlotte'.

Charlotte

## EDUCATION SESSIONS - JUNE 2016

### Lymphoma "All You Need to Know" - Seminar

Dirksland, Netherlands - 06/09/2016

[Click here for details.](#)

### MDS Patient Forum

Copenhagen, Denmark - 06/11/2016

[Click here for details.](#)

### Hodgkin's Lymphoma Interactive Meeting

Stockholm, Sweden - 06/18/2016

[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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