

## Our Mission



Worldwide network of 71 lymphoma patient organisations from 48 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 LC Members:

Lymphoma Coalition is pleased to formally announce the launch of the **Standards of Excellence (SoE) program**.

The 2016 Global Patient Survey clearly demonstrated that patients need information and support beyond what they receive from their healthcare professionals. While patient organisations can help fill this gap, patients are not always referred to one by their doctor or nurses. Further research uncovered trust and respect are at the core of strong relationships between physicians and patient organisations, and this is largely linked to how an organisation operates.

Lymphoma Coalition created the SoE program to assist all member organisations with improving and publicly showcasing the standards by which they operate, and **ultimately drive more patient referrals after diagnosis**.

It's set up in a modular format so organisations can work at their own pace. It's important to remember that the goal of each of the four modules is not to necessarily create uniform policies across all organisations, but instead to have consistent high standards of operation that are rooted in high-quality patient-centric support.

Once you have successfully completed a module, you will receive an electronic badge (as shown below) you can place on your website and social media properties, along with text to help you communicate your achievement to your community.

All Lymphoma Coalition member organisations are encouraged to participate in the SoE program.

For more information, visit the members section of the [LC website](#) (you will need to log in) or [email me](#).

For those of you joining us at the Global Summit in Atlanta, Georgia, USA, we look forward to seeing you next week. It will be a great opportunity for learning and sharing. As always, we will also take some time for fun. If you are curious about what our special members event entails, your only hint is **swipe card**. Remember to pack comfortable closed-toe shoes for this event.

You should have received information regarding the summit by email, but if you have any lingering questions about logistics, please [contact Kim](#) and any other questions can be sent to me.

As always, thanks for the work you do supporting patients.

Warm regards,

*Kaun*



GOVERNANCE



INFORMATION STANDARDS



ORGANISATIONAL PROCESS & CONTINUITY PLANNING



FINANCIAL ACCOUNTABILITY & FUNDRAISING



## 2017 Report Card on Lymphomas

The 2017 Report Card on Lymphomas, which focuses on overcoming impediments to patient care, will be launched at the Global Summit.

For those not attending, you will be able to find the report card on 6 December [here](#).

### New Report

## Burkitt Lymphoma

A subtype report on [Burkitt lymphoma](#) has been added to the [9 subtype reports](#) already available on the LC website.

We encourage you to read this report and learn more about the key issues facing patients, especially those who live in resource-challenged countries.

Our thanks to Lauren Pretorius, CEO, Campaigning for Cancer, for her guidance creating this report.

A report on Hodgkin lymphoma in Europe will be available in December.



Hodgkin lymphoma (HL) patients are facing numerous problems affecting their quality of life on an emotional, physical and economic level.

The Lyfe app can help.

Lyfe provides:

- ✓ Insightful articles from credible sources;
- ✓ Practical tips for all stages of the patient journey;
- ✓ The ability to connect with others locally, nationally and across the globe.

The app was recently updated and is now available in 4 languages:

**English \* French \* German \* Spanish**

Four advertisements will appear in the medical journal [Blood](#) through November and December to inform the medical community of the availability of Lyfe, with the goal for them to refer the app to patients. Information on the app will also be distributed at the LC booth at the ASH conference.

In addition, the Lyfe app will be marketed on social media to targeted populations, to help ensure HL patients are aware of this support tool tailored for them.

Lyfe is free and available from Google Play and the App Store for iOS. For more information, please visit: <http://www.lyphomacoalition.org/lyfeapp>.

## Research News

There will be a lot of research information released in early December, related to the annual [American Society of Hematology \(ASH\) conference](#). As always, Lymphoma Coalition will be in attendance at this conference and will send out links to key research announced at ASH in our December newsletter. There is currently a great deal of activity in the lymphoma research community and we anticipate there will be much to share.

In the meantime, here are some recent updates for your information:

- [Patients' priorities in selecting chronic lymphocytic leukemia treatments](#)
- [Varying Pertinence: MRD Testing Across Lymphomas](#) (Video interview)
- [TP53 mutations identify younger mantle cell lymphoma patients who do not benefit from intensive chemoimmunotherapy](#)
- [Incorporation of brentuximab vedotin into first-line treatment of advanced classical Hodgkin's lymphoma](#): final analysis of a phase 2 randomised trial by the German Hodgkin Study Group
- [PI3K Inhibitors: Understanding Toxicity Mechanisms and Management](#)



Connect with us online!

[lyphomacoalition.org](http://lyphomacoalition.org)  
Contact Us

## Team Update

Dear European Members:

As the Regional Coordinator Europe, I hope that you will find great value in the information communicated in this newsletter. You'll find news from our field, educational information, upcoming events and activities from LCE members. Please share your success stories with us! You will inspire others who face similar challenges.

I want this newsletter to be valuable to you so [please provide feedback and suggestions](#) to help us improve future issues. I look forward to working with you all!

- Natacha

Stay tuned!

A Regional Director will be announced very soon.

## Regulatory & Access News

A new treatment has been approved by the EMA:

- [Adcetris \(brentuximab vedotin\) to treat CD30-expressing cutaneous T-cell lymphoma \(CTCL\)](#).

The EMA has agreed to review documents supporting the approval of [Mogamulizumab](#) — an antibody targeting the CCR4 protein — for adults with advanced cutaneous T-cell lymphoma (CTCL) who have received at least one prior systemic therapy. Full results of the Phase 3 MAVORIC study will be announced at the 59th ASH Annual Meeting & Exposition on 11 December.

## Member Activities



LYPA has launched an online education platform for Serbian patients, providing a wide range of educational programs for lymphoma patients, survivors and their loved ones, including videos, infographics and more. LYPA is working now on an English version, to expand their work cross-borders, planned to be launched in December 2017. [www.bloodcancer101.org.rs](http://www.bloodcancer101.org.rs)



The Slovenian Association of Patients with Lymphoma and Leukemia, L & L, in partnership with the Association of Hematologists of Slovenia and various experts in the field of integrated rehabilitation, is implementing a [comprehensive rehabilitation program](#) for patients with blood cancer, co-financed by the Ministry of Health.

This free pilot program is intended for patients in active therapy and for 6 months after completion of treatment. It consists of three modules: physical exercise; nutrition; and psychosocial support, all led by healthcare professionals and complemented by monthly consultations on a variety of topics.

Magyar  Rákellenes Liga® Have you seen [Misszió](#) ("Mission")? It's a 50-minute film about the Hungarian Cancer League, showing the great work of their volunteers, created by a stellar team that includes an award-winning documentary director and screenwriter.



Cancer & Equal Care in Sweden: The Swedish municipalities and county councils (SKL) work together with the Regional CancerCentrum (RCC) to make cancer care more patient-focused, accessible and equal. The Swedish Blood Cancer Association has contributed to developing the criteria for the establishment of a national care program with level structuring, standardized and multidisciplinary care and contact nurses. These criteria will ensure that investigation, treatment, nursing, rehabilitation and patient follow-up will be promoted, promoting that all patients will have access to the best expertise in the country as required.

## Welcome to Amsterdam, EMA!

Amsterdam will host the European Medicines Agency (EMA) once it leaves London after Brexit. Amsterdam was one of the preferred locations by EMA employees. EMA Executive Director Guido Rasi expressed relief: "Amsterdam ticks many of our boxes," he says in a statement the agency sent out. The agency is scheduled to take up its operations there by 30 March 2019. Because of its important role to safeguard public and animal health in the EU, EMA is committed to giving stakeholders and the public full visibility of the relocation project. In early December, the Agency will make available a monitoring chart on its website that will allow to track the progress made. Move information is available [here](#).



Connect with us online!