

## Our Mission

LYMPHOMA  
COALITION

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:

With the high degree of focus on “patient centricity”, the LC Board of Directors thought it was important to define what this term means, on behalf of the patient body who are the recipients of the behaviour that is driven by this term.

### Patient centricity has been defined as follows:

- ❖ Engaging individuals with lymphoma, and their caregivers, in all aspects of their care, tailoring support with the understanding that every patient is unique with a different set of complex needs that may change over time.
- ❖ Giving the lymphoma patient, and those close to them, a voice so that the focus of their care and needs are included throughout the decision-making process.
- ❖ Listening to and hearing the person affected by lymphoma respecting their culture, input, dignity, intelligence and capacity to make informed decisions about the impact on their lives and their care.
- ❖ Including patient organisations as active partners representing a patient’s emotional and psychosocial needs at every stage of care including; treatment, protocol development and by informing research throughout the clinical and treatment development continuum.

The [International Lymphoma Patient Charter](#) has been updated to reflect this definition and is now available on the LC website.

This is an important piece of work for LC as this definition is one of the key criteria we will be using to decide where to focus our energies and how to measure the success of future activities. It is presently being translated into French, German and Spanish. If you would like to adopt this for your organisation, please translate it and send it to us for layout.

If you have not already spent time considering what patient centricity means to your organisation, we encourage you to use this one or create a definition that is representative of your organisation’s beliefs. It is an important tool to show to your members, and the general public, that you are dedicated to putting the best interests of patients at the centre of your work.

Please take a moment to read through the important updates provided in this newsletter. We hope the information will help support your work and further the needs of patients.

As always, I appreciate all that you are doing to help patients on a daily basis. I look forward to seeing you at the Global Summit in December!

Warm regards,

Karen

## Welcome New Members

We are pleased to announce new members have joined our [global family](#). LC now includes 71 member organisations from 48 countries. Please join us in welcoming:

- [Leukemia Patients Care Association](#), Iraq
- [Blodkreftforeningen](#), Norway
- [Korea Blood Cancer Association](#)





## Hrvatska Udruga Leukemija i Limfomi (HULL) (Croatian Leukaemia and Lymphoma Society), Croatia

When Dražen Vincek was diagnosed with chronic myelogenous leukaemia (CML) in 2010, he thought he was going to die. “I was very unhappy, crying and afraid. But then I heard from doctors and others about [HULL](#) (Hrvatska Udruga Leukemija i Limfomi) and that there are many different kinds of help and medicines available,” said Dražen, who is the president of HULL, an association for patients with a blood cancer and other haematological diseases, and their caregivers in Croatia.

Following his diagnosis, Dražen got involved with HULL so he could help others in similar situations.

HULL was started in 1994 with the express purpose of helping patients obtain the expensive treatments needed for leukaemia, lymphoma and other haematological diseases. The other objectives of HULL are to:

- Inform patients about new treatments;
- Encourage the improvement of medical standards in haematological departments;
- Encourage the education and professional training of physicians and nurses.

“We had the leading haematologists in Croatia help us form the organisation. Today, we have a steering committee that comprises 10 patients and 10 doctors,” he said.

Thank you, Dražen, and your team at HULL for the help you give those with a haematological disease as well as their families. Read the entire article [here](#).

## Standards of Excellence Program

LC created the Standards of Excellence program for you to help improve and demonstrate your high standards of operation, and in turn improve trusting relationships with local healthcare professionals and patients. An email was sent out inviting you to join a webinar on 16 November to learn more about the program. Please plan to attend. For more information, contact [Karen](#).

2017 meeting videos  
now available!



The International Lymphoma Epidemiology Consortium is a group of scientists who undertake research projects that pool data across studies to better understand lymphoma causes and risk factors. Lymphoma Coalition is a proud sponsor of this meeting.

Videos are now available on the [LC website](#) and on the [LC YouTube channel](#), featuring leading researchers discussing key findings on the following topics:

1. Genetics
2. Hodgkin lymphoma
3. Circadian rhythms
4. Occupational risk factors
5. Physical activity
6. General risk factors.

New Report

## Cutaneous Lymphoma Report

A [new report on cutaneous lymphoma](#) has been added to the [8 subtype reports](#) already available on the LC website. We encourage you to read this report and learn more about the key issues facing patients. Our thanks to Susan Thornton, CEO, [Cutaneous Lymphoma Foundation](#) for her guidance creating this report.

A report on Burkitt lymphoma will be available in early November.

## WhiMSICAL

If you are a patient with Waldenstrom's macroglobulinemia (WM) and want to participate in the first patient- and medical researcher-led patient database, we encourage you to click [here](#) for more information on WhiMSICAL. It is used to capture data from patients globally. If you are not a patient, you can help by promoting WhiMSICAL to WM patients.



Connect with us online!

lymphomacoalition.org  
Contact Us

## Team Update

Progress is being made! We are close to announcing new team members for LCE.

If you have any questions or require support in the meantime, please reach out to Guy, Sarper or [Karen](#).



## Recent Activities



On behalf of LCE, Sarper presented at the 2017 e-Health Forum, Greece.



LC Members at the European Cancer Organisation (ECCO) patient advisory committee meeting.

## New Report

## Lymphoma Care in Europe: Gaps and Disparities in Patient Care

The European report is now available. It highlights disparities in access and adequate care in Europe. Care includes treatment, clinical trials, personal support and credible information.

Lymphoma is among the most active cancers for research as well as the introduction of new therapies, including novel targeted therapies, immunotherapies and a growing array of therapies used in combination. However, it still takes five to eight months longer, on average, to approve lymphoma therapies in Europe than in the USA. There are also ongoing inconsistencies in access to drugs by patients by country. While the wide disparities are in novel therapies, differences were also found in availability of longstanding standard treatments.

Clinical trials are critical for improving lymphoma treatment, but wide disparity in availability in Europe was found. As well, rare lymphoma subtypes appear underserved by research compared with the most common forms of lymphomas.

Also impacting care is wait time to treatment, financial concerns, lack of personal support, doctor-patient communication and the psycho-social impact of the disease. European healthcare systems typically do not consider patients' quality of life as much as they should.

The report makes seven recommendations to help improve care.

Click [here](#) to download the report *Lymphoma Care in Europe: Gaps and Disparities in Patient Care*.

## Research News

From the Grupo Español de Linfomas/Trasplante de Médula Ósea (GELTAMO) network (Spain): [Long-term results of a phase 2 study of rituximab and bendamustine for mucosa-associated lymphoid tissue lymphoma.](#)

From Dr. Gilles Salle (France): [Rituximab in B-Cell Hematologic Malignancies: A Review of 20 Years of Clinical Experience.](#)

From the German Hodgkin Study Group (Germany): [PET-guided treatment in patients with advanced-stage Hodgkin's lymphoma \(HD18\): final results of an open-label, international, randomised phase 3 trial.](#)

From the European Congress on Immunotherapies in Cancer (Spain): [Immunotherapy agents have shown significant activity in patients with Hodgkin lymphoma and made a marked difference in treating patients with relapsed or refractory disease, according to Javier Briones, MD, PhD.](#)