

# NODE NEWS

MEMBER NEWSLETTER | JUNE 2018

LYMPHOMA  
COALITION

Worldwide Network of  
Lymphoma Patient Groups



Dear LC Member,

The Global Summit is a week away and we are very excited to see each other in person to share activities and learn from each other. It feels like a homecoming. You will find the [agendas](#) for the main Global meeting and the regional breakouts on the members section of the website under 2018 Global Summit.

In time for the Global Summit are two reports that you will find quite interesting; an overview on CAR-T Therapy in Lymphoma Today and an update on Biosimilars. These will be available in hard copy at the Global Summit and can be found on the website [here](#). Please feel free to use these articles as a reference, educational piece for patients and translate them and use them on your websites. The reports are available as a Word document in the members section to help you customise for local use, [here](#).

The Global Patient Survey reports, including 14 country reports and the global report, are now available and can be found [here](#). Congratulations to the 14 members who worked hard to reach 100+ respondents to ensure they had their by country information analysed and reported. The European report and the subtype reports will be available by the end of July.

The survey data confirms that those that were more informed during their patient experience felt confident and felt that they had better outcomes. This compliments the work in the [The Knowledge Age: 'Better' Outcomes for 'Informed' Patients?](#) report that Natalie Dren wrote and presented at the December Global Summit highlighting the research work of Drs. Jessica Green and Judith Hibbard. These results remind us of the importance to encourage your medical community to refer patients to credible sources such as patient organisations, for information and ongoing support.

Thank you for all you have done so far this year to support patients with lymphoma. We recognise your long days and hard work and we are hoping that the Global Summit will both encourage and rejuvenate you as you work through the back half of the year.

Kindest regards,

Karen

## MEMBER SPOTLIGHT



ASOCIATIA ROMÂNĂ  
ÎMPOTRIVA LEUCEMIEI

Founded in 2006, the mission of Asociația Română Împotriva Leucemiei (ARIL) is to improve the chances of recovery for current and future patients with hematological diseases in Romania by acting to improve treatment conditions.

Up until 2012, ARIL reported a heavy focus on sending both patients and healthcare professionals abroad to receive treatment or specialised training. Though these practices continue, ARIL's recent efforts have focused on better equipping Romania to provide patients with the care they need.

Find out more about ARIL and their work for patients [here](#).

## RESEARCH NEWS

- Tisagenlecleucel Demonstrates Durable Response Beyond 1 Year in DLBCL [READ MORE](#)
- Update on Hairy Cell Leukemia [READ MORE](#)
- Phase 3 Trial of Ibrutinib plus Rituximab in Waldenström's Macroglobulinemia [READ MORE](#)
- Five years of ibrutinib in CLL [READ MORE](#)
- Selected Update on Lymphoma from EHA 23 Congress [READ MORE](#)

## ASIA PACIFIC

LYMPHOMA  
COALITION  
ASIA PACIFIC

Dear Members,

It is wonderful to be in the role and be underway connecting with members and mapping out and understanding the very different challenges faced by our members in the Asia Pacific region. An important focus will be to better understand each member's local environment and the similarities and differences across the region. Additionally, there had been a very good response from our members in the region to the Lymphoma Coalition Global Survey and we look forward to sharing these insights and learnings.

We have a wonderful opportunity coming up to meet face to face at the Global Summit in Prague in July 2018 to share learnings and get to know each other further. The programme at the Global Summit is valuable and will bring us together to spend time with our global colleagues also. We will keep you posted on details in the meantime.

Pru

## EUROPE

LYMPHOMA  
COALITION  
EUROPE

Dear Colleagues,

Lymphoma Coalition Europe's work has been dominated in recent weeks by the European Haematology Association's 23rd annual congress in

## 23rd EHA Congress

Stockholm, Sweden. Although the scientific and research updates and presentations are at the heart of EHA 23, the congress is also an opportunity for lots of other initiatives and work to be done.

While Natacha and I were at the Congress, we participated in progress meetings for the HARMONY Big Data project, along with just over 50 other organisations, mainly clinical and research institutions and pharmaceutical companies. The aim of this EU-funded, five-year project is to bring together clinical and research data for some haematological malignancies (including lymphomas and CLL) from the public and private sectors, harmonise it and then analyse it for agreed research questions. In addition, the project seeks to agree a consistent set of core outcome measures (including quality of life outcomes) that we will be included in all future trials and research. LCE's role in the project is to provide the perspective of lymphoma patients and we're also closely involved in the workstream that is reviewing the Magnitude of Clinical Benefit Scale (originally developed by the European Society of Medical Oncology) to see how it can be adapted for haematological malignancies.

We also attended and contributed to the discussions between EHA's European Affairs Committee (EAC) and the leaders of the umbrella organisations for the European haematology patient organisations. The EAC is an important part of EHA with a membership drawn from the past, present and future presidents, along with other key haematologists and opinion leaders. The EAC is planning to develop a lobbying and advocacy programme, in partnership with patient advocacy organisations, focusing on two or three key issues and probably will include equitable access to new treatments across Europe. I am also pleased to report that I was appointed to the Committee last month as one of three patient organisation members, and I hope this will ensure that LCE's views and opinions can feature more strongly in EHA's future work.

Alongside everything else that was going on at EHA, we also had many fruitful meetings with current and prospective industry partners and it was pleasing to see the support for the new LCE strategy and plan that was signed off by Lymphoma Coalition's Board of Directors last month. LCE's newly re-formed Advisory Committee has also reviewed the strategy and plan, providing very useful input and insight, and we're looking forward to sharing it when we see you at the Global and Regional Summit in Prague in July.

Until then, best wishes

Jonathan

## Lymphoma Coalition Europe Regional Meeting



There is just over a week left until the Lymphoma Coalition Europe Regional Meeting starts in Prague. Over the past few months, LCE has been working hard to set up an attractive programme to enhance knowledge on how to increase our effectiveness as advocates.

Don't miss this meeting!

It will include exchanging ideas, alliance-building, networking & sharing best practices, with important learnings for you to bring back to your own organisation. As this meeting is within the framework of the Lymphoma Coalition Global Summit, you will also have the opportunity for networking across borders.



The program covered over 200 oral sessions and 1,300 posters. From a record number of submitted abstracts, the Scientific Program Committee and the Advisory Board compiled a program that offered something for everyone.



Lymphoma Coalition Europe members and many other Patient Advocates were an important part of the meeting. For several years, patient organisations have organised a "Patient Advocacy Track" within the scientific program during the congress, and share our work at the Patient Advocacy HUB, a joint booth of all European patient advocacy organisations within the exhibition.

Immunotherapy certainly made waves during the congress. There was lots of discussion and excitement around CAR-T therapy, especially for patients with diffuse large B-cell lymphoma who have not responded to other treatments, but also a recognition that there are still issues with CAR-T that need to be addressed.

Sessions covered many other important developments for lymphoma patients in the use of standard therapies, biosimilars, improvements in precision diagnosis, patient assessment and follow up and quality of life issues. Topics included current perspectives and future direction in follicular lymphoma, how to control CLL using new drug combinations, optimisation of first-line treatment in classical Hodgkin lymphoma, effectiveness of PET-guided treatment de-escalation in advanced Hodgkin lymphoma and improvement of patient assessment through incorporating patient relevant outcomes into research and clinical practice, among other interesting topics.

[CLICK HERE](#) for a summary of the EHA congress, with a lymphoma focus.

All of the EHA congress content is available at [EHA's Learning Centre](#).

Patient advocates can easily [become EHA members](#) as guests (no payment required!)



*Patient advocates at EHA.*

## ESMO Consensus Conference on malignant lymphoma: Management of 'ultra-high-risk' patients

This ESMO consensus conference manuscript on 'ultra-high-risk' patients with malignant lymphoma was compiled by a multidisciplinary panel of 25 experts. It provides clear guidance on the management of the following high-risk situations: DLBCL with CNS relapse, primary refractory HL and PBL. Recommendations provided are accompanied by relevant supporting evidence. [READ MORE](#)

