



Dear LC Members,

Welcome to the new version of the Lymphoma Coalition Node News members newsletter! We hope you like this simplified format. It will continue to be a valuable source of information for you on LC and member activities, only in a different style. As always, we welcome your feedback. If there is anything you can recommend that will help us improve the style and content of the newsletter, please email [marketing@lymphomacoalition.org](mailto:marketing@lymphomacoalition.org)



The Standards of Excellence Program is now available in the members section of the [website](#). If you believe your organisation fulfils the criteria for one or all of the badges, you can complete the online submission, upload the supporting documents and be one of the first organisations to earn a badge.

The next quarterly review date for submissions is 28 February 2018. If you require assistance with completing this work, please [email me](#).

I wish everyone great success in 2018 and look forward to hearing about your achievements.

Warm regards,

Karen

## LC Member Organisations now have HNHCP Membership

The Haematology Nurses and Healthcare Professionals Group (HNHCP) is an international non-profit organisation established to support nurses and other healthcare professionals through the rapidly evolving landscape of haematology and enable them to deliver optimal care to patients and support their families.

Now more than ever, well informed healthcare professionals are needed to help patients and their loved ones cope with the complexity of living with a haematological disease and enable them to achieve the best possible quality of life.

For those of you that attended the Global Summit, you will remember the valuable information shared by HNHCP vice chair Mairéad Ní Chonghaile concerning HCP & patient communication.

LC respects the work HNHCP is doing and believes there are many opportunities where we can work together to improve patient outcomes. As such, **LC has arranged for all its member organisations to become members of HNHCP.**

You can find out more about HNHCP at [www.hemcare.org](http://www.hemcare.org).



Rosmarie Pfau, *ho/noho* - Schweizerische Patientenorganisation für Lymphombetroffene und Angehörige; Lorna Warwick, LC; Anita Waldmann, Leukaemihilfe RHEIN-MAIN e.V. (LHRM) attended the HNHCP Educational Conference in Zurich.

## GLOBAL PATIENT SURVEY

The 2018 Global Patient Survey for Lymphomas and CLL is now live. We sincerely apologise for the delay in launching the survey, but it was necessary to ensure all 19 language translations were accurate. Please encourage patients and care providers to take the survey. This data is important to all our work, ensuring the patient perspective stays at the heart of all we do. The survey will remain open until 7 March 2018.

[CLICK HERE FOR SURVEY LINK](#)

## WELCOME: KOREA BLOOD CANCER ASSOCIATION!



The Korea Blood Cancer Association became an associate member of LC in September 2017.

Find out more about the organisation and their amazing work for patients [HERE](#)



## Update from the 2017 ASH Meeting

- Listen to the MP3 of the educational event hosted by the Lymphoma Research Foundation & CancerCare [HERE](#)
- Review the coverage provided by the CLL Society [HERE](#)

## RESEARCH NEWS

- Lenalidomide/rituximab not better than standard of care in follicular lymphoma [READ MORE](#)
- Five-year results of brentuximab vedotin in patients with relapsed or refractory systemic anaplastic large cell lymphoma [READ MORE](#)
- CLL: The Risk of Richter's Transformation [WATCH VIDEO](#)

## ACCESS

Novartis will stop commercial availability outside of the USA for Ofatumumab (Arzerra) for CLL. The drug will be only provided through compassionate use programs for patients currently being treated with Arzerra as an ongoing treatment, to ensure continuity of treatment. Chemoimmunotherapy with fludarabine, cyclophosphamide, and rituximab (FCR) remains the standard of care for first-line treatment of CLL. [READ MORE](#)

## LCE NEWS



Dear LCE Members,

Welcome to 2018!

Already it is a productive year for many. I'm very pleased to share my experience so far in LCE. Since starting in October, I have been working with partner alliances and learning how to strengthen the scale and impact of our work as a Coalition in Europe. It's very encouraging to know about the great work you do at your country level and we want you to know that LCE is here to help you, so I would be happy to hear from you.

Don't hesitate to write me!

Natacha

## ACCESS

- The European Medicines Agency (EMA) has granted an accelerated assessment to a marketing authorization application for Kymriah (tisagenlecleucel), for the treatment of adults with relapsed or refractory diffuse large B-cell lymphoma (DLBCL). This CAR T-cell therapy, previously called CTL019, will be approved for patients who have relapsed after a stem cell transplant or are not eligible for one. [READ MORE](#)
- European Commission approves ADCETRIS® for CD30-positive cutaneous T-cell lymphoma after one prior systemic therapy, an important milestone for the CTCL community in Europe. [READ MORE](#)

## ADVOCACY NEWS

### Bulgarian Lymphoma Association



Last December, following protests from patients' organizations, the Bulgarian parliament made a U-turn on its own decision to halt public funding for innovative medicines for cancer and other rare diseases, which would have left thousands of patients without access to treatment. [READ MORE](#)

### Lymphoma Coalition Europe is going to support EHA's Madrid Declaration



The Madrid Declaration calls upon the European Commission to increase the minimum length of haematology training required for the automatic cross-border recognition of haematologists from three to five years, with the aim to harmonize training requirements across Europe. [READ MORE](#)

### Lymphoma Coalition Europe adds value to Clinical Practice Guidelines



LC started a collaboration to advise guideline developers on identifying topics that are important for patients, such as quality of life, symptom management, and to find a way to integrate patient's values and preferences. LC is partnering with ESMO to review the new CPGs for haematology malignancies or for the management or conditions that affect lymphoma patients. [READ MORE](#)