

NODE NEWS

MEMBER NEWSLETTER | MARCH 2019

LYMPHOMA
COALITION

Worldwide Network of
Lymphoma Patient Groups



Dear LC Members,

The **2019 Global Summit will be held October 2 & 3 in Barcelona**. We are in the midst of planning another informative, interactive agenda, including timely topics like gathering and using data effectively to guide priorities and support advocacy work, advocacy tips and tools, as well as latest lymphoma information affecting treatment decisions. There will of course be time for networking and fun, including a member event on the evening of Day 1. Industry partners will join us on Day 2, with a group reception at the end of the day.

Like last year, **each member organisation is invited to send one person** to the meeting and travel grants will be provided to attendees. Attendees should plan to arrive in Barcelona on 1 October and leave on 4 October. Hotel costs will be covered for 3 nights (1, 2 & 3 October).

More information will be coming soon on how and when to register. Hopefully, every organisation will be able to join the summit.

The very first LCE Community Advisory Board is happening in Brussels 2-5 April. This is the first time a lymphoma-specific CAB is being held. During CAB meetings, lymphoma and CLL-focused CAB members join with representatives of pharmaceutical companies and research groups to discuss key issues. The aim of the CAB is to influence the research and development pipeline for treatments to better meet the needs of patients; increase access to, and reimbursement of, treatments; improve awareness and understanding of lymphomas; create a louder voice for the lymphoma and CLL patient community; and recruit, train and support more patient advocates and experts for individual countries and Europe as a whole.

Information on meeting learnings & outcomes will be available in the next newsletter. While the focus is Europe, it is anticipated outcomes will apply to many other parts of the world.

Sincere thanks to the people who have volunteered their time to participate in the CAB, which includes not only attending the meetings but also ongoing training. It is a dynamic, dedicated group focused on doing their best to well represent lymphoma/CLL patients.

If you want to learn more about the CAB, please reach out to [Jonathan](#) or [Natacha](#).

Best regards,

Lorna, Pru & Jonathan

Spotlight on the Patient Experience Poster

LC has prepared a visual summary of the 2018 report card, highlighting key issues and challenges identified in each stage of the patient experience using the 2018 Global Patient Survey results.

[DOWNLOAD THE POSTER HERE](#)

RESEARCH NEWS

- Integration of cell of origin into the clinical CNS International Prognostic Index improves CNS relapse prediction in DLBCL [READ MORE](#)
- BCL-2 emerges as an attractive target in solid and hematologic cancers [READ MORE](#)
- BMT societies issue recommendations on posttransplant maintenance in HL/NHL [READ MORE](#)
- AUGMENT: A phase III study of lenalidomide plus rituximab versus placebo plus rituximab in relapsed or

refractory indolent lymphoma

[READ MORE](#)

- The prognostic and clinicopathological significance of PD-L1 expression in patients with diffuse large B-cell lymphoma: a meta-analysis [READ MORE](#)
- EBMT 2019 | Preliminary in-human evaluation of a CD19/CD22 dual CAR-T construct for B-NHL [READ MORE](#)

ASH 2018 REPORT

[Click here](#) to read a summary of some of the ASH 2018 Annual Congress presentations. If you are interested in a specific session not included in this summary please contact [Natacha](#).

WELCOME NEW MEMBER

LC is pleased to welcome [The Association of Patients with Hematological Malignancies - Slovakia](#)

The perspective and participation of our global family is integral to ensuring patients have a level playing field of information, so they have access to the best possible care in a timely manner.

WLAD 2019



Join us for a **World Lymphoma Awareness Day** Launch webinar on **17 April at 8:00AM EDT or 8:00PM EDT.**

Invitations will be sent out shortly.

PROUD OF OUR MEMBERS

***Tree of Life* patient support program in Latvia**

The Oncological Patient Support Society *Tree of Life* is tirelessly reiterating that life continues after cancer! It is often radically different as values, perceptions of life, goals and priorities change. *Tree of Life* promotes mutual support when needed. In addition, *Power Source* is a psychosocial rehabilitation program, with support groups and mentoring. Since 2018, psychosocial rehabilitation is a state-funded program supported by the Ministry of Welfare. More than 1300 people from all over Latvia have already participated in the programs. Real people and real rehabilitation that inspires life! [READ MORE](#)

ADVOCACY



Challenges of Providing Access to Innovative Medicines in the Countries of Eastern Europe

Eastern Europe belongs to quite a different healthcare milieu compared to the developed Western economies. While many of the Balkan countries nominally guarantee universal healthcare coverage through compulsory health insurance, in reality there are numerous obstacles in providing healthcare services. Particularly, patients face several barriers accessing innovative treatments as they are not included in the basket of reimbursed services, and there are delays in approvals and pricing decisions. While many of the most essential medicines and devices are reimbursed in principle for all citizens, the reality is that governments have cut health budgets in recent years, so many face shortages or a complete lack of accessibility to the latest treatments, and some of the poorer countries often find it difficult to maintain access to even basic technology. LCE is increasingly looking to cooperate more closely with members to support their advocacy actions. **In April, LCE will be circulating letters to some Balkan Countries authorities to call attention to these issues and demand their commitment to improved access to innovative treatments and lymphoma care.**

ALLIANCES

Patients expanded involvement at the 45th EBMT Annual Meeting 2019 in Frankfurt



[The Patient, Family and Donor Day](#) at the European Society for Blood and Marrow Transplantation (EBMT) Annual Meeting has become an integral part of the yearly [EBMT congress](#) since it was first introduced at EBMT Lyon 2007. For the first time in Frankfurt 2019, the Patient, Family and Donor Day expanded to include two parallel sessions, bringing content for patients, family members and donors, and for patient advocates. One of the main goals was to improve the communication between EBMT professionals and patients. This is increasingly relevant due to the rapid evolution of technology associated to transplantation and its relationship with the growing field of cellular therapy. The introduction of new drugs and graft manipulation techniques, combined with changes in the clinical pattern of transplantation, particularly in the outpatient setting, has led to remarkable developments in the field over the last few years. The programme was aimed at exploring both scientific trends and the special relationship which is often created between the clinical BMT personnel and patients and their families. [Click here to Follow EBMT Lymphoma on Twitter](#)

