



Dear LC Member,

What an amazingly successful Global Summit, held July 6-7 in beautiful Prague. How does one describe the global family unit that has grown into such a sharing community willing to support each other and share best practice? As Pru Etcheverry has said many times, "Aren't we lucky?"

There were 41 attendees from 31 countries and on day 2 we were joined by 13 pharmaceutical partners, who participated in round table discussions on best practices and helped generate ideas on how to address gaps in care.

The format was a little different this year as the regional meetings were held inside the Global Summit. This was done for a few reasons - we wanted to cut down on the number of meetings, save costs and ensure that all members are given the opportunity to meet each other, make connections, speak about their key achievements and learn from others within the regional and the global settings.

The [presentations](#) are now available in the members section of the website under Annual Global Summit and we encourage you to reach out if you have any questions or comments as you apply these learnings within your organisational plans. If you need a password to sign in, contact [Karen Royds](#).

Overall, the evaluations from the Global Summit were very positive and we appreciate the feedback. It will be used to develop next year's meeting. The [summary](#), as well as the many photographs that capture some of the moments and emotion of the meeting can be found in the members section as well. If you have more photos that you would like to share, please email them to [Karen Royds](#).

For those who could not attend, we missed your presence and hope you will join us next time. Dates for next year are being reviewed and a notice will be sent out by the end of September, so everyone can save the date.

Please remember to review the [2018 Global Patient Survey on Lymphomas & CLL](#) reports and wrap this great data on patient experience into the work that you do. The learnings from this survey guide our work, ensuring we stay patient-centric and communicate an authentic patient voice. To date it has been well received by the medical communities and the Coalition members.

Feel free to reach out to [Lorna Warwick](#) if you would like some support on presentation slides or pulling more information for you locally.

Enjoy the pictures!

Warmly,

Karen

BOARD OF DIRECTORS: A SPECIAL WELCOME TO MONICA PASQUALIN

MEMBER SPOTLIGHT



When Jean Pierre Blondeel was diagnosed with low-grade follicular lymphoma in 2002, he began seeking information and support beyond what was provided by his doctors. Jean Pierre connected with other Belgian lymphoma patients and for many years worked towards bettering patient conditions in Belgium. In 2015, he founded Hodgkin en non-Hodgkin vzw, a non-profit lymphoma organisation recognised by the Belgian government.

Hodgkin en non-Hodgkin vzw has certainly grown since its beginnings; Jean Pierre acts as president, and now has a team of 5 full-time staff, numerous volunteers, a board of directors, and over 200 patient members.

Find out more about Hodgkin en non-Hodgkin vzw and their work for patients [here](#).



RESEARCH NEWS

- Kahl Shares Antibody-Drug Conjugate Updates in Lymphoma [READ MORE](#)
- Ibrutinib May Be Effective as First-Line Agent in Treatment of Waldenström's Macroglobulinemia [READ MORE](#)
- Dr. Humphrey on Mogamulizumab for Cutaneous T-Cell Lymphoma [READ MORE](#)
- Mutations in Half of Patients With CLL Who Relapse on Ibrutinib [READ MORE](#)
- Up-front Rituximab Maintenance Improves Outcome in Patients with Follicular Lymphoma: A Collaborative Nordic Study [READ MORE](#)

STANDARDS OF EXCELLENCE

Congratulations to the below organisations who have achieved SOE modules in the last evaluation phase:

- [Campaigning for Cancer, South Africa](#) (now have all 4 four modules as they recently achieved Financial Accountability and Fundraising, and Information Standards)



Monica is the new member to the Board of Directors announced at the Annual General Meeting on 6 July. She is the Head of Strategic Alliances, Fundraising at ABRALÉ – Brazilian Lymphoma and Leukemia Society. She also heads the Alianza Latina programme at ABRALÉ, coordinating a network of 122 patient advocacy institutions across Latin America, the USA, Spain and Portugal. Click [here](#) to read her full biography.

GET INFORMED

Check out LC's latest articles on [CAR-T Therapy in Lymphomas Today](#), and [An Update on Biosimilars in Lymphoma](#). You can read them [HERE](#).

- [V Care Foundation, India](#) (3 modules - Financial Accountability and Fundraising; Information Standards; Governance)
- [LIPA Lymphoma Patients Association, Serbia](#) (2 modules - Governance, and Information Standards)

WLAD WEBINAR

Join us for an overview call of WLAD 2018 to ensure you have the information you need for a successful campaign in September!

Wednesday 8 August at 14:00 CEST

Register for the webinar [HERE](#)

REMINDER: if you would like any of the WLAD posters translated, please send your translations to marketing@lymphomacoalition.org, by 10 August.

ASIA PACIFIC



Dear Members,

It was an important and exciting milestone to officially launch Lymphoma Coalition Asia Pacific (LCAP) at the Global Summit in Prague!



The Global Summit also included the opportunity for LCAP members to participate in their first regional meeting. Our time together was spent understanding the various challenges members face, organisationally and within each represented country's political and healthcare systems. Although, as expected there are great regional differences, key themes common to all soon emerged.

The aims for this inaugural face-to-face meeting were:

- To allow everyone the opportunity to participate;
- To build an LCAP advocacy community;
- To establish ways to best communicate as a group;
- To identify key needs and unmet needs;
- To find the common areas we can affect change that can be applied locally;
- To assess areas where LC can best support.

From the group's feedback, we are confident these first steps were achieved. We are now in the process of setting up a dedicated WhatsApp group and an LCAP email group for those interested, and are looking forward to those LCAP members who were unable to attend the Global Summit joining in.

The need for effective patient organisations is as strong as ever, as is the need for sound advocacy strategies to ensure the patient voice is brought to the table wherever needed. In some countries this is new territory and we will explore together ways to support this important work. LCAP is also working to actively build a bank of knowledge for the region that all members can use and share where relevant. This includes data from the Global Patient Survey and the various country reports.

Best wishes,

Pru

EUROPE



LCE REGIONAL MEETING

Many LCE members met together during the **LCE Regional Meeting**, part of the LC Global Summit. The sessions were facilitated by Stefan Gijssels, who provided practical learnings on **key tools used in influencing advocacy, power-mapping and stakeholder analysis, policy context and development of policy briefs**. Members also shared their best practices and table groups discussed gaps and challenges. Important messages and actions to take forward will be shared soon with all LCE members. There were interesting lectures about "**value definition**", including Gilly Spurrier providing the patient view on the ESMO Magnitude of Clinical Benefit Scale (MCBS). The session also included advice on how to read and analyse scientific journals and clinical trials data. Natalie Buhl and Patrick Bonnet provided the pharma perspective on how patient experience data supports clinical and cost-effectiveness decisions. Lastly, Rob Camp introduced the role of a **Community Advisory Board** and why it could be relevant for the lymphoma community.

Thank you to everyone who attended for your participation and

NEWS FROM EUROPE

First Two CAR-T Cell Medicines Recommended for Approval in the European Union

The European Medicines Agency (EMA) has recommended the approval of two lymphoma medications: Kymriah (tisagenlecleucel) and Yescarta (axicabtagene ciloleucel).

Kymriah is indicated for the treatment of paediatric and young adult patients (up to 25 years of age) with B-cell ALL that is refractory or in second or later relapse, and in adult patients with relapsed or refractory DLBCL after two or more lines of systemic therapy.

Yescarta is indicated for the treatment of adult patients with relapsed or refractory DLBCL and primary mediastinal large B-cell lymphoma (PMBCL), after two or

contributions.

All the sessions were recorded. The full content of the LCE Regional Meeting is available [here](#).



LCE IS PROUD OF ITS MEMBERS

Viver + (Live +): Physical and Psycho-emotional Rehabilitation Program for Patients and Cancer Survivors

Developed by the Portuguese Association of Leukemias and Lymphomas (APLL), led by their president Dr. Isabel Leal Barbosa, this program focuses on improving the quality of life of patients and cancer survivors through physical rehabilitation and psychological intervention. It aims to achieve a progressive increase in flexibility and mobility, reduction of social isolation and fatigue management. Classes are guided by specialised trainers, who in addition to the physical training component also promote mutual support and sharing amongst participants. According to the evaluation of the Viver + project to date, all respondents consider their participation in the program essential to their recovery and that the practice of physical exercise has improved their quality of life in various areas such as mobility, muscular strength, socialization, the reduction of isolation, and emotional health.

[Viver + was the winner of the Celgene 2017 Prize in Portugal.](#)

more lines of systemic therapy.

[CAR-T therapy](#) offers an innovative approach where patients' own immune T-cells are reprogrammed to improve their ability to fight cancer.

Both products are the first treatments supported through EMA's Priority Medicines (PRIME) scheme to receive positive opinions from the Committee for Medicinal Products for Human Use (CHMP). The scheme provides early and enhanced scientific and regulatory support to treatments that have the potential to significantly address patients' unmet medical needs.

[READ MORE](#)

IN MEMORY

Last Farewell to Franco Mandelli, a Man of Extraordinary Humanity



The lymphoma community paid their last respects to professor Franco Mandelli, haematologist, 87-years-old, President of the Italian Association Against Leukemia, Lymphoma and Myeloma (AIL). For Mandelli there was a disease to defeat, but there was a sick person to take care of, putting the patient at the centre, not the disease. He became a leading figure in the fight against blood diseases, in particular against Hodgkin lymphoma and acute leukaemia. [READ MORE](#)

