

NODE NEWS

MEMBER NEWSLETTER | APRIL 2019

LYMPHOMA
COALITION

Worldwide Network of
Lymphoma Patient Groups



Dear LC Members:

I am currently at an interesting meeting - the [AAADV Annual Workshop](#) (Accelerating Anticancer Agent Development and Validation). The programme includes a global session, a day that allows investigators, regulatory experts, and drug developers involved in global anti-cancer drug development to interact. The day included speakers from China, India, Europe, Singapore, Japan, Canada, Korea, Australia, Nigeria and the US. A portion of the meeting surrounded the patient voice and how it is (or not) included in the regulation of treatments. Many countries/regions focus on the patient voice being part of funding or reimbursement decisions, but this takes it back one step further. Regulators admit this is an area they struggle with as they don't know how to best incorporate patients into the process, with the FDA in the US the only one doing so regularly. What I appreciate here is the willingness by some (not all yet) to talk about it and to investigate ways they could include patients, and the fact that the conference embraces participation by patient advocates. I do think we will see some movement in this area and look forward to more discussions with people I met here about how to move this forward.

I will also be attending the [ASCO](#) meeting the first part of June, Natacha will be at the [EHA Congress](#) in mid-June, Natacha and I will both be at

RESEARCH NEWS

- Study confirms initial monitoring strategy effective in MCL [READ MORE](#)
- EBMT 2019 | A consensus grading system for toxicities in CAR T trials [READ MORE](#)
- Understanding the limitations of CAR-T Cell Therapies [READ MORE](#)
- Molecular pathogenic pathways in extranodal NK/T cell lymphoma [READ MORE](#)
- The management of primary mediastinal B-cell lymphoma: a British Society for Haematology Good Practice Paper [READ MORE](#)

[ICML](#) later in June, and Natalie will be at the [InterLymph](#) meeting the end of June. If you will be attending any of these meetings, please make sure you let us know so we can connect. Reports will follow with key learnings from the meetings, as well as videos. There should be some very important learnings coming from each of these meetings.

We look forward to seeing many of you in Barcelona in October for the Global Summit! The programme is shaping up well and there are some really great initiatives from member organisations that will be profiled. If your organisation has an initiative that you are proud of, please share with [Lorna](#), [Pru](#) or [Natacha](#) as we love to hear about your work. The Summit will also be the first time the *Karen Van Rassel Leadership Award* is presented. More information will be available soon about this award.

You should have received an email with the information needed to register for the Summit. If you have any questions or concerns, please contact [Kim](#).

Best regards,

Lorna

CELGENE HEME GRANT PROGRAM

REMINDER - don't miss the opportunity to participate in the inaugural *ImpactHeme Award* competition.

The theme for the award is 'Supporting Shared Decision Making' in Hematology and **five prizes of \$20,000 USD** each (or equivalent in local currency) will be awarded to five organisations.

- Novel combinations making their way to frontline setting in CLL [READ MORE](#)
- Final results of a randomized, phase III study of rituximab with or without idelalisib followed by open-label idelalisib in patients with relapsed chronic lymphocytic leukemia [READ MORE](#)

WLAD 2019 MEETING



For full details, visit www.impacttheme.com. The **deadline to apply is 18 May 2019** and the winners will be announced on 15 June 2019.

Thank you to all who joined the WLAD call on 17 April. For those of you who were unable to attend the meeting, you can find the [call recording and presentation on the Member's side of the LC website, HERE](#). (Login is required. If you don't have a login or have forgotten your login, please contact [Karen](#).)

To help further develop this year's WLAD campaign, please complete a short survey providing feedback on the 2018 WLAD materials, as well as the plans for 2019. This survey will ensure members have the tools needed for a successful campaign. [Take the survey HERE](#).

Thank you for your participation. We look forward to sharing more WLAD materials in the coming weeks.

PROUD OF OUR MEMBERS



AIL Presents the Italian report of the LC 2018 GPS at National Meeting

On 13 April in Alcona, the [Italian Lymphoma Patient Group](#), together with the [Italian Association against Leukaemia, Lymphoma and Myeloma \(AIL\)](#) and supported by the [Italian Lymphoma Foundation \(FIL\)](#), organised a national meeting involving doctors, patients and caregivers. During the meeting, doctors focused their speeches on patients' needs and took questions from patients and caregivers. The national meeting is held twice a year and all the video recordings are available on the [AIL YouTube channel](#). AIL also presented the

Italian report of the 2018 Lymphoma Coalition Global Patient Survey, and thanks to cooperation between LC and AIL, the report has been translated into Italian and is available on the [AIL website](#).

Mercy Bridge Attends the Russian Hodgkin Lymphoma Conference

The Russian lymphoma organisation [Mercy Bridge](#) attended the Russian Hodgkin Lymphoma Conference. Mercy Bridge had a very active role setting up a desk where patient information and LC reports were presented and disseminated, along with explanations on the value of patient organisations to mend the gap between doctors and patients. In addition, they organised a concert with the help of musician student-volunteers and their professor, as part of the conference's opening.

ALLIANCES

HARMONY Update

The HARMONY T-cell Lymphoma Consortium will meet face-to-face in the framework of the ICML in Lugano. Would you like to know more? Let us know! Contact [Natacha](#).

ADVOCACY

Does health matter in the European Parliament elections?

The upcoming European Parliament elections will perhaps be the most scrutinised ever, as a bellwether for the wellbeing of the European project. With health considered to be one of the issues resonating most with Europeans (in a recent Eurobarometer survey, 70% of European citizens wanted more action on health) it can be argued that strong leadership on health from the European institutions will bring the EU closer to them, and can help to restore trust. The [European Public Health Alliance \(EPHA\)](#) has carried out an initial analysis of the manifestos or publications setting out the groups' positions for the elections in May which have been published to date. [LEARN MORE](#)

