

NODE NEWS

MEMBER NEWSLETTER | SUMMER 2019

LYMPHOMA
COALITION

Worldwide Network of
Lymphoma Patient Groups



Dear LC members:

Thank you to everyone who has registered for the Global Summit. A record number of participants have registered and we look forward to seeing many of you in Barcelona in October! More information on the Summit is available in the member's section of the website [here](#). If you have any questions relating to the Summit, please contact [Kim](#).

It has been a busy conference season. There are updates in this newsletter on both the [European Hematology Association \(EHA\) congress](#) and the [International Conference on Malignant Lymphoma \(ICML\)](#).

One of the things of note this year is the number of negative trials being reported, which are trials that did not meet their hoped for endpoints. It is important to remember that negative results are still significant scientific advances as they reinforce that current standard of care is the best option for patients and also helps focus future research towards other opportunities. For example, studies looking at new therapies for DLBCL did not meet their desired endpoints, which means

RESEARCH NEWS

- Current and prospective therapies for double-hit lymphoma [READ MORE](#)
- Mantle cell lymphoma: 2019 update on the diagnosis, pathogenesis, prognostication, and management [READ MORE](#)
- Long-term safety of single-agent ibrutinib in patients with chronic lymphocytic leukemia in 3 pivotal studies [READ MORE](#)
- ASCO 2019 | Obinutuzumab plus venetoclax is superior than combination with chlorambucil in naïve CLL with comorbidities [READ MORE](#)
- ASCO 2019 | No benefit with rituximab maintenance following complete remission for diffuse large B-Cell lymphoma [READ MORE](#)

that R-CHOP is still the best therapy for front-line treatment of DLBCL even though it has been in use for a number of years.

In addition to the usual scientific updates, ICML featured presentations focused on the high cost of cancer drugs. The presentation by Dr Vincent Rajkumar of the Mayo Clinic received a standing ovation. While his presentation at ICML is not available on video, a similar talk he gave is available [here](#). It is interesting to see medical practitioners starting to engage more in this area, recognising they might be able to influence lower prices.

Lymphoma Coalition had an abstract published in the ICML abstract book titled *A Cross-Sectional Study Examining How Knowledge of Lymphoma Subtype Affects The Patient Experience*. It is part of the ongoing research into informed patients reporting better overall experiences, and is available [here](#).

September is fast-approaching and plans for World Lymphoma Awareness Day 2019 (WLAD) are well underway. The new WLAD website will launch next week. Please plan to join us for webinars on 21 or 22 August to ensure you have all the last-minute information needed for another successful campaign. Any questions on WLAD can be directed to [Karen](#).

Best regards,

Lorna, Natacha and Pru

- *EHA 2019* | Acalabrutinib monotherapy safe, significantly improves PFS in Relapsed/Refractory CLL [READ MORE](#)
- *15-ICML* | Identifying genetic alterations associated with relapse in DLBCL [READ MORE](#)
- Factors associated with long-term fatigue in non-Hodgkin lymphoma survivors [READ MORE](#)

WLAD 2019 UPDATE



The World Lymphoma Awareness Day website www.worldlymphomaawarenessday.com will be launching the week of August 5th. On the website you will find materials to help promote WLAD, such as:

- briefing guide
- campaign poster
- lymphoma fact sheet
- fact infographics
- social media profile photos and cover photos

Webinars are currently scheduled for:

International Lymphoma Epidemiology Consortium (INTERLYMPH)

June 24-27 marked the annual meeting of [INTERLYMPH](#) in Bordeaux, France. Formed in 2001, the Consortium is a group of international investigators who have completed or have ongoing case-control studies (relating to lymphomas), who discuss and conduct research projects that pool data across studies or otherwise undertake collaborative research.

LC was in attendance this year to hear about exciting findings, as well as ongoing and upcoming studies from working groups focused on: genetics, immunology and infection, pathology and survival, lifestyle and environment, family, multiple myeloma and Hodgkin lymphoma.

LC had the opportunity to conduct video interviews with members of each working group to better understand their current studies, relevant results, and future goals. We also spoke to thought leaders pertaining to pesticides and lymphoma, breast implant associated anaplastic large cell lymphoma (BIA-ALCL), and current research in Hodgkin lymphoma biomarkers. These videos will be posted on the LC website towards the end of August — stay tuned!

- 21 August at 8pm EDT ([find your local time](#))
- 22 August at 8am EDT ([find your local time](#))

You will only need to attend one webinar. Meeting details will be sent out shortly.

We look forward to another very successful WLAD on September 15!

NEW LC REPORTS

- [Subtype Report: Diffuse large B-cell lymphoma](#)
- [Selection of sessions from *The 15th International Conference on Malignant Lymphomas \(ICML\)*](#)
- [Selected update on Lymphoma from *the 24th Congress of the European Hematology Association EHA*](#)

The LC team is excited about starting a project for Asia Pacific around mapping, tracking and reporting on systems and policies. The aim is to bring visibility to the region by providing a unique perspective on the world of lymphomas to support advocacy. Part of this project will

be to establish a baseline of information to map the countries in the region to see where patients and patient organisations are able to engage in processes.

We will be gathering data at a country-level on:

- disease-specific differences identifying the most common lymphoma subtypes and treatment and clinical trial access
- cancer registries, where they are, and are not, and what they are capturing
- regulatory environment to improve understanding of how drugs come to market in members' countries, including drug approval processes, time to approval, and reimbursement
- HTA systems scan, mapping where these systems exist by country and what is in place if no formal HTA processes exist
- patient experience data using global patient survey, stories and case studies

We have seen wonderful examples of how powerfully data from LC's Global Patient Survey can be used to support advocacy and hope that this will further add to that data.

We are starting with information that is publicly available, then building the data to address gaps through key opinion leaders and verifying with local sources. So we'd love to talk further with all our members in the region as we progress. Thank you so much for your wonderful help so far.

PROUD OF OUR MEMBERS

AIL Celebrates 50th Anniversary

In July, a delegation from [AIL - The Italian Association Against Leukemias, Lymphomas & Myeloma](#), met with the Minister of Health Giulia Grillo on the 50th anniversary of the Foundation. The meeting followed the participation of AIL in the Health Pact Marathon, an occasion in which three proposals were presented concerning equity in access to care, health mobility and pharmaceutical governance. [READ MORE](#)



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Lymphoma Action on BBC News

Stephen Scowcroft from Lymphoma Action appeared on BBC Newsroom Live on 21 June 2019 commenting on a CAR T-cell therapy segment. [Click HERE to view the clip.](#)



Hematon Introduces Patient Job-Search Assistance Project

It is well known how challenging it can be to return to work after being diagnosed with lymphoma. The '*Work as Medicine Project*' helps patients define who they are and what they are good at, with the focus on how to approach a work experience placement. Patients are introduced to participating employers on the basis of their current CV (after diagnosis), with the objective of finding the most suitable position possible. [READ MORE](#)



Blodcancerförbundet Winner of the ImpactHeme Grant Award

Congratulations to [The Sweden Blood Cancer Association](#) on winning the [ImpactHeme Grant Award](#), an international competition focused on how to promote shared decision making in healthcare. They were awarded a grant to work on their '*Mapping Support*' program, which aims to provide care staff with support for person-centered communication, while at the same time gaining a better understanding of the choice of intervention / aftercare services that are most suitable for the unique person being treated. [READ MORE](#)

Patient-Related Measures

In 2018, Blodcancerförbundet, published the results of their project on *patient-related measures (PREM/PROM)*, based on the hypothesis that the PREM instruments that are used today do not necessarily contribute optimal data to support patient-centric decision-making. They have now received support for a follow-up project '*Patient-related Measurements 2.0*' to develop diagnostic-specific outcome and experience measures. [READ MORE](#)

“Sowie Oczy” focus on CTCL

The first Polish study of the quality of life of patients with cutaneous T-cell lymphoma (CTCL) was launched with support from the [Polish Lymphoma Association](#), alongside the campaign: *Lymphomas, which we do not know. A problem that we do not see*. This project is aligned with the *Cutaneous Lymphoma – Spreading the Word* project, promoted by Lymphoma Coalition Europe, now available on the LCE website. [READ MORE](#)

IWMF Educational Forum

The [International Waldenstrom's Macroglobulinemia Foundation \(IWMF\) Forum](#) is a unique opportunity for patients and caregivers to learn about the disease from specialists in WM who are involved in many areas of clinical practice and research. It provides attendees with the opportunity to share experiences with others travelling the same WM journey. The 2019 IWMF Educational Forum proved to be a huge success, with over 350 people in attendance. It was also an event of firsts, including the first ever “great debates”, in which noted WM experts debated key WM treatment questions. Also, for the first time, a keynote presentation – by Dr. Steven Treon, MD,

PhD of Dana Farber Cancer Institute – was available live on both YouTube and Facebook. [CLICK HERE](#) to view all the videos of the main speakers at the forum.

ALLIANCES



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Open consultation ICH guideline E19 on optimisation of safety data collection: Patient involvement required by 29/09/2019

Patient organisations are called to provide regulators with their perspective on safety data collection. Although safety monitoring of patients during clinical studies remains critically important, unnecessary and burdensome data collection may serve as a disincentive to participation in clinical studies, e.g., frequent and time-consuming patient visits; laboratory tests; and/or physical examinations. The ICH guideline E19 explores under what circumstances a targeted approach to safety data collection in some late-stage pre-marketing or post-marketing studies would be appropriate and how to implement such an approach. This approach could reduce the burden to patients which can serve as a disincentive to participation in clinical research, while recognising that protection of patient welfare during medicine development is of critical importance. The aim is to enable a larger number of informative clinical studies to be carried out with greater efficiency and greater global participation in studies, for the benefit of public health. [READ MORE](#)

Consultation: Horizon Europe - Orientation towards strategic planning

Patient organisations have an interest in future EU research and innovation priorities, therefore should have lots to say when it comes to identifying what the most pressing challenges are that EU-funded research and innovation should tackle. The European Commission is preparing the implementation of Horizon Europe in an intensive co-design process. The process will help shape European research and innovation investments in the coming years. As part of the process, the Commission has launched an [online consultation](#).

Lymphoma Coalition encourages its membership to participate in the consultation which closes on **8 September 2019**.

For more information on the European regulatory system for medicines, please [click here](#) (brochure available in many languages).

Masterclass in Cancer Patient Advocacy – recommended by ESO

The Masterclass on Patient Advocacy was originally initiated by ESO (European School of Oncology) and took place three times between 2014 and 2018. It is now being taken forward by the patient community as the WECAN Masterclass in Cancer Patient Advocacy.

From 6-9 July 2019, WECAN held the first Masterclass on Patient Advocacy, aiming to address common educational needs of the patient community. The [WECAN Academy](#) trains cancer patient advocates from all over Europe in three educational pillars: [Advocacy Tools & Skills](#), [Healthcare Systems](#), [Policy & Access](#) and [Research & Data](#). [CLICK HERE](#) to read about some impressions of participants of the WECAN Academy 2019.

