

# NODE NEWS

MEMBER NEWSLETTER | FEBRUARY 2019

LYMPHOMA  
COALITION

Worldwide Network of  
Lymphoma Patient Groups



Dear LC Member,

The Lymphoma Coalition has come a long way from 2002 when a small group of patient advocates recognised the need for a vehicle for collaboration, information sharing and joint learning. The Coalition now has 80 member organisations in 51 countries, all focused on improving the lives of those affected by lymphoma.

Since the LC founding in 2002, the lymphoma world has also changed considerably. There are many more defined subtypes, new therapy classes, expanded research, more targeted therapies, increasing cost issues, problems with access to quality care and increased need for patient-centricity in all areas. The world in general has also changed with novel technologies, information availability and global connectivity.

Taking all of these factors into account, the Board and leadership of LC is in the process of creating a new strategic plan to take us through the next 10 years. We all recognise the good works of the Coalition over the last 16 years, and we also recognise there is more we can do moving forward.

You, our members, are still our focus and valuable partners. The LC will continue to be an information source and support system, encouraging sharing and learning from each other. In addition, the LC will strive harder to be an advocate for those affected by lymphoma in arenas where member organisations don't have a voice and provide leadership for well-thought-out change (based on quality information) that will have large-scale impact.

The process includes an updated vision and mission statement, that will reflect LC's role as a driver of change that will lead to improved lymphoma outcomes. More information will be available soon as the plans progress.

If you have any questions in the meantime, please contact one of us.

Best regards,

[Susan](#) (Board Chair), [Lorna](#) (CEO), [Jonathan](#) (Regional Director Europe) and [Pru](#) (Regional Director Asia Pacific)



*From left to right: Sarper Diler (Secretary/BIRKAN, Turkey), Lauren Pretorius (Director/Campaigning for Cancer, South Africa), Lorna Warwick (CEO), Rosmarie Pfau (Vice Chair/[lymphome.ch](http://lymphome.ch), Switzerland), Susan Thornton (Chair/Cutaneous Lymphoma Foundation, USA), Kim Drever (Director of Global Operations), Guy Bouguet (Treasurer/France Lymphome Espoir, France), Jonathan Pearce (Regional Director Europe), Pru Etcheverry (Regional Director Asia Pacific), Monica Pasqualin (Director/ABRALE, Brazil).*

## RESEARCH NEWS

- Phase II DYNAMO trial: Duvelisib in heavily pre-treated R/R iNHL patients [READ MORE](#)
- High CXCR4 expression impairs rituximab response and the prognosis of R-CHOP-treated diffuse large B-cell lymphoma patients [READ MORE](#)
- Fixed duration of venetoclax-rituximab in relapsed/refractory chronic lymphocytic leukemia eradicates minimal residual disease and prolongs survival: post-treatment follow-up of the MURANO phase III study [READ MORE](#)
- Expert highlights real-world findings with axi-cel in DLBCL [READ MORE](#)
- Low-dose R-CHOP yields similar survival benefits compared with standard dose in elderly patients with DLBCL [READ MORE](#)

## GLOBAL SUMMIT SAVE THE DATE

This year's global summit will take place:

**2 & 3 October in Spain**

Details coming soon.

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## WELCOME NEW MEMBERS

LC is pleased to welcome:

- [Lymphoma Patients Association of Romania](#)
- [CLL Greece](#)
- [Italy - Gruppo Abruzzese Linfomi](#)
- [CLL Ireland](#)

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

## Cutaneous Lymphoma 'Spreading the Word' Project

The cutaneous lymphoma patient's guide has been translated into 30 European languages. They will be circulated in early March to member organisations for review and amendment, for translation accuracy and for the inclusion of local information. Although the timescales have slipped slightly, the project should be completed in March 2019 and it is hoped this will be a major contribution to meeting the information needs of cutaneous lymphoma patients throughout Europe. For further information on this project please contact either [Jonathan](#) or [Natacha](#).

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## Lymphoma and CLL Community Advisory Board (CAB)

There have been two rounds of recruitment for membership of the Lymphoma/CLL CAB that is being set up in partnership with EURORDIS Rare Diseases Europe. About 30 applications were received from people who want to join the CAB. The first CAB members conference call for those who have joined already happened at the end of February. There will be follow-up conference calls for new members in March, along with the provision of training for all CAB members. The first face-to-face CAB meeting has been confirmed for 1 to 5 April 2019 in Brussels, Belgium, where 12 CAB members will meet with three pharmaceutical companies to discuss agenda topics including new treatment protocols in chronic lymphocytic leukaemia, CAR T-cell therapy and new therapies in follicular lymphoma and diffuse large B-cell lymphoma. All being well, further meetings will be held

the first week of July and early November. For further information on this project or to get involved, please contact either [Jonathan](#) or [Natacha](#).

## LC IS PROUD OF ITS MEMBERS



### **Congratulations to V Care Foundation, India on its 25th Cancer Survivors' Day**

V Care celebrated their 25th anniversary with many events surrounding their annual Cancer Survivors' Day. Events included a musical program for cancer patients and their families from Tata Memorial Hospital; "Holy Darshan" for patients staying at various dharamshalas; notable TV personalities joined cancer survivors at Tata Memorial Hospital to distribute winter clothing to patients; and various buildings in the community were lit up purple to show their support for V Care Foundation. [LEARN MORE](#)



### **Feed your health. Let food be your medicine.**

In January 2019 biologists Dr. V. Laganà and Dr. V. Sofia in collaboration with haematologist and founder of the Association Dr. Caterina Stelitano started a project which aims to provide nutritional information and guidance to lymphoma patients and care providers. It is not enough to simply introduce nutritional food, as it is important to know how to eat, calculating the micro and macronutrients essential to an appropriate energy requirement, the latter necessary for a better approach to therapies. [READ MORE](#)

### **Kristina Modic, CEO of the L & L Association recognised by Jana Magazine in Slovenia**

Every year Jana Magazine nominates ten Slovenian women, who are each noticeable in their field. These women stand out from the average as they devote their time and energy to helping improve the lives of others. Amongst the nominees for 2018 was Kristina Modic, Executive Director of the Lymphoma & Leukemia Association. She is extremely proud of this honour, since the nomination is a recognition of the efforts of all active members who, together with Kristina, form a strong and successful team of advocates for



SLOVENSKO ZDRUŽENJE  
BOLNIKOV Z LIMFOMOM IN LEVKEMIJO

blood cancer patients. [READ MORE](#)

LyLe chatted with hematologist Dr. Francesco d'Amore, Dr. Mette Dahl and PhD students at the Clinic for Blood Diseases at Rigshospitalet, about the recent development in the understanding and treatment of hematologic diseases. "Looking at CLL for example, which is one of the most frequently occurring leukaemia diseases, there has been a considerable development within a few years in how we treat CLL, taking into account the mutations the individual patient has. In addition, there is a growing focus on the patient not only having to survive, but actually also having a good life after the treatment", says doctor Mette Dahl. [READ MORE](#)

