



Dear Members,

We are very pleased to welcome Jonathan Pearce as the Lymphoma Coalition Europe (LCE), Regional Director, effective 1 March 2018. Having spent the last four years as the chief executive of the Lymphoma Association in the UK, as well as previously serving as a board member for Lymphoma Coalition, Jonathan is a respected, familiar face within our community.



Jonathan has over 15 years' experience as a charity chief executive. His strengths lie in his ability to grow charities' influence and support. He joined the Lymphoma Association in December 2013 and led the charity through an ambitious and exciting phase of development, resulting in a significant increase in its reach and impact. It was through this role that he first became familiar with Lymphoma Coalition (LC). His first-hand experience of the value of bringing organisations together with a shared goal of improving the lives of patients with lymphoma, led him to join the LC Board in 2015, serving as a Director. He is also

Chair of Cancer52, a national alliance in the UK of charities representing rare and less common cancers.

We are thrilled that Jonathan is joining LCE. Having worked with him in the past, we are fully aware of his many talents, his dedication to improving the lives of patients with lymphoma, as well as his significant achievements at the Lymphoma Association. The future for LCE is limitless with Jonathan at the helm.

Jonathan told us that he is delighted to be joining LCE. Having personally benefitted from being part of the global LC, he is aware of the value of the learning opportunities and the networking with other patient organisations facing similar successes and challenges that LC membership brings. He is looking forward to continuing the valuable work of LCE and partnering with the European member organisations to make positive changes for patients across Europe.

Jonathan and Natacha Bolaños, Regional Coordinator, will work together to achieve the goals and objectives of the LCE.

You may welcome Jonathan at [jonathan@lymphomacoalition.org](mailto:jonathan@lymphomacoalition.org). He will continue to be based in the UK.

Warm regards,

Karen

## STANDARDS OF EXCELLENCE



Thank you to everyone who has participated in the Standards of Excellence Program. We will be reviewing completed submissions on 28 February.

You still have time to participate. **Did you know that the Information Standards badge only requires you to have 3 support documents?** It is a great first badge to earn! It is important as it shows your

commitment to credible information sources, which the medical community truly values in non-profit organisations.

If you believe your organisation fulfils the criteria for one or all of the badges, you can complete the online submission, and upload the supporting documents. The program can be found on the LC website [HERE](#) (please ensure you are signed in as a Member).

## GLOBAL PATIENT SURVEY

The 2018 Global Patient Survey for lymphomas and CLL is ongoing, and we are looking forward to sharing the results with everyone. Thank you for your continued efforts in promoting participation, and we encourage you to keep up the momentum as the survey will be open until 7 March 2018. The more responses we receive the more robust and acceptable the data will be.

[CLICK HERE FOR SURVEY LINK](#)

## WLAD 2018

Last week, a conference call was held with members to discuss this year's proposed theme for World Lymphoma Awareness Day (WLAD) 2018, *The Small Things Build Confidence*. If you were unable to attend the meeting, [CLICK HERE](#) to download a recording.

We are enlisting further feedback and it is important to the messaging. Please complete a very short questionnaire providing feedback on WLAD 2017, your organisational plans for WLAD 2018 and thoughts on this year's proposed theme. [CLICK HERE](#) to provide feedback.

## RESEARCH NEWS

- **Autologous transplant in follicular lymphoma after treatment failure** [READ MORE](#)
- **Physical Activity Raises Survival Rates of Patients With Lymphoma** [READ MORE](#)
- **Frailty and the management of hematologic malignancies** [READ MORE](#)

## Congratulations V Care on your Successful Cancer Survivor Day!

[V Care Foundation](#) organised the 24th Cancer Survivor's Day. Events included hospital visits, gifts for patients and a [Funtakshri](#). The 2018 activities culminated with the [Victor Awards](#) ceremony. The awards include:

- *Lifetime Achievement Award* for significant and remarkable contribution and service by an individual in cancer care.
- *Victor Awards* highlight the strength and courage of a Survivor who has gone beyond his/her own recovery and contributed positively to help others overcome their struggle, and who's living life to the fullest with great enthusiasm and zest.
- *Care Giver Award* recognises and praises the crucial contribution of a Care Giver in the treatment and recovery of a patient.
- *Humanitarian Award* for those whose dedicated voluntary service has made an exemplary positive difference in the lives of others.

Don't miss the deadline.

If you require any assistance with completing this work, please [email Lorna](#).

## WELCOME NEW MEMBERS!

The following two organisations became full members of LC in January 2018:



**Hodgkin en non-Hodgkin vzw** supports patients with lymphoma across Belgium. They are focused on ensuring patients feel empowered. Find out more [here](#).



جمعية مما لمصارية سرطان الفقد للمفاوية  
Association Ensemble Contre le Lymphome

**Ensemble Contre le Lymphome (ECL)** aims to inform, support, and improve the care of patients with lymphoma in Morocco. Find out more about their achievements [here](#).

The Romanian Association against Leukemia (ARIL) became an associate member in January.



ARIL was founded to improve the care and support for patients with hematological diseases in Romania. Find out more about their activities [here](#).

## LCE NEWS



### LCE is Proud of its Members

Dear LCE Members,

The more we get to know the LCE members' work, the prouder we become of this dynamic community of patient organisations. We are appreciative of your commitment to serving lymphoma patients, your problem-solving skills and creativity, and your high standards. Highlighted in this section are some recent activities of LCE members that illustrate your efforts.

Warm regards,

Natacha



**HULL**

#### Hull is part of the "Hugs for rare diseases" awareness campaign

The Croatian Association of Leukemia and Lymphoma (HULL) actively cooperated in this important campaign, with about 20 participants' cities in 20 days, 2000 km and 200,000 hugs. HULL's new booklet "Chronic lymphocytic leukemia/small cell lymphoma" was promoted during this campaign. The event was accompanied by excellent media coverage.

In addition, HULL promoted a lecture on the subject "Biosimilars: flies or elephants" which was held by Prof. Dr. SC Igor Aurer, head of the Institute for Hematology of the Clinic for Internal Diseases KBC Zagreb. Learn more [HERE](#).



#### The Finnish Cancer Patients Association strengthens the involvement of patients through the use of international networks

The Finnish Cancer Patients Association (SSP) is carrying out a Funding Centre for Social Welfare and Health Organisations (STEA)-funded project: "Communication Strong, the Patient Point of View - Information and Support for International Networks". Active patients participate in identified cancer-specific, international patient organizations and networks' activities, including seminars, electronic workshops and other events. These patients then bring new ideas, information and good practices they learn from these activities to cancer patients and SSP to support its operations. The project plays an important role in lobbying for medicines, for example, by bringing information related to pharmaceutical research, drug development and authorization procedures to Finnish patients, with a focus on improving the capacity of patient organizations to provide patients' impact reports to the Pharmaceuticals Pricing Board (HILA). Learn more [HERE](#).



#### Educational Videos

Do you need to have a PET / CT scan or a bone marrow biopsy? LymfomHelp has created educational videos to help blood cancer patients understand individual tests, how to prepare for them, what happens during the test and possible complications, and to learn more about their disease. [CLICK HERE TO WATCH](#)



#### Patient-Reported Experience Measurement project:

An in-depth study of patient experiences in healthcare from the perspective of a person living with a chronic blood cancer diagnosis in Sweden today

Blodcancerförbundet (the Blood Cancer Association) received funding from the National Board of Health and Welfare to investigate patient-reported experience measures (PREM) as they relate to chronic blood cancer patients. The resulting report identifies several areas to improve in blood cancer care, including support, treatment, coordination and self-care.

Blodcancerförbundet plans to follow through by launching two projects to address issues identified in the report. View the project report [HERE](#).

### CONGRATULATIONS TO THE FOLLOWING MEMBERS:



#### Lyle: LCE thanks you for the ten remarkable years of advocacy, warmth and support!

Each year, approximately 2,600 Danes are diagnosed with lymphoma, leukemia or MDS, and the number is increasing. Today, 20,000 Danes live with hematologic cancer. LyLe's history dates back to 2007, and today is a well-established, independent and active patient association for people affected by these diseases. Lyle counts on more than 1,000 members and has built 9 network groups in Denmark.



#### ho/noho is now Lymphome.ch Patientennetz Schweiz

ho/noho in Switzerland has a new name. The organisation is now called **Lymphome.ch Patientennetz Schweiz**.

The original name came from Hodgkin (ho) and non-Hodgkin (noho). The change is due to the term non-Hodgkin no longer being used in the updated WHO classification and a recognition of how important it is for patients to identify with their specific subtype of lymphoma. LC congratulates Lymphome.ch Patientennetz Schweiz on putting their patient needs first and rebranding to match their beliefs. Learn more about them [HERE](#).