



Dear LC Members,

World Lymphoma Awareness Day is quickly approaching. See below for some items to help your organisation create awareness.

MEMBER EVENTS

We will be featuring all Member's WLAD events and celebrations on the LC website. Please send your details to [Marketing](#) to have your WLAD event listed.

SOCIAL MEDIA COVER PHOTOS

The WLAD 2018 Facebook and Twitter cover photos are [now available for use on the Members Section of the LC website](#) (login required). Feel free to email [Marketing](#) if you would like us to add your member organisation's logo on the social media cover photos.

Please add these cover photos to your social media pages by 30/31 August.

PATIENT/CARER MESSAGE ABOUT WLAD

To encourage patient and carer activity on Facebook during WLAD, we have developed a message you can provide to your Facebook followers / email subscribers. You can find the message on the [Members section of the LC website, under COMMUNICATIONS DOCUMENTS, titled "Patient/Carer Message about WLAD"](#). We suggest you send this message out as early as possible.

WLAD UPDATE MEETING

If you missed any WLAD update meetings, you can find the recordings and presentations on the [Members section of the LC website](#).

Please email [Marketing](#) if you have any questions, or need any assistance accessing the WLAD documents.

Thank you for your support and we look forward to a successful WLAD this September!

Warmly,

Karen

RETIREMENT ANNOUNCEMENT OF KAREN VAN RASSEL, CEO

As announced in July, Karen Van Rassel will be retiring from her role as CEO of the Lymphoma Coalition at the end of 2018. Karen is going to be a first-time grandmother very soon and is moving to be closer to her family. Karen has been a strong, respected leader of LC through the years and has been an integral part of its growth and success to date. We will all miss her but understand her decision to focus her time and energy on her family.

An update on the search for a new CEO will be provided to members shortly. Any questions about the transition process can be sent to [Kim Drever](#).

RESEARCH NEWS

- Dual Immunotherapy Adds Value in Relapsed/Refractory Hodgkin Lymphoma [READ MORE](#)
- Exercise and Cancer [READ MORE](#)
- Staging of Mycosis Fungoides and Sézary Syndrome: Time for an Update? [READ MORE](#)

STANDARDS OF EXCELLENCE

Reminder that the next deadline for submissions for the Standards of Excellence is **31 August**.

ASIA PACIFIC



There are two upcoming meetings, where Lymphoma Coalition Asia Pacific (LCAP) members will be featured. We wish them well and look forward to hearing about their success.

[7th China Rare Disease Summit](#) – Shanghai, China - 14-16 September:

Held by the Chinese Organization for Rare Disorders, this year's focus is raising awareness of rare cancers. The participants include relevant government departments, HCPs, pharmaceutical companies, patients, families, and media.

Hong Fei Gu from [House 086](#) in China is presenting and a chair at this meeting and is organising one section of the cancer series.

[UICC World Cancer Congress](#) – Kuala Lumpur, Malaysia - 1-4 October 2018:

A recognised international biannual conference encouraging knowledge transfer and best practices sharing amongst 3,500 cancer control and public health experts from 150 countries. The congress aims to strengthen the participants' action and impact on national, regional and international scales through a multidisciplinary programme that features the latest successful interventions in cancer prevention, diagnosis, treatment and care.

Two of our LC members are presenting at this meeting: Vandana Gupta from [V Care Foundation](#) in India and Hong Fei Gu from House 086 in China.



LC will be represented by Pru Etcheverry with a booth at the [2018 International Conference on Cancer Nursing \(ICCN 2018\)](#), 23-26 September in Auckland, New Zealand, her home town. Pru will have the opportunity to promote the global aspect of the LC members as well as LCAP. ICCN is the world's premiere meeting for nurses interested in cancer care, providing the opportunity to engage with leaders in cancer nursing from around the globe, participate in conversations that will shape cancer nursing research and translate evidence-based cancer nursing education, practice and research into patient-centred care. This year's conference theme is Global Actions: Working Towards Unity and Excellence in Cancer Care. Currently, there is a free conference registration available if any member is planning to attend. If you plan to attend, please let [Pru](#) know so you can arrange time to connect.

LCAP IS PROUD OF ITS MEMBERS



Support and Hope for those touched by cancer

V Care Foundation, India, is marking 25 years in operation. This is an enormous milestone and testament to the outstanding work of the voluntary team there and the tireless work of the founder Vandana Gupta. Find out more about their work here. Also of note, V Care Foundation have recently been nominated for an [iVolunteer Award](#) in the category '[Leader in Volunteer Engagement](#)'. **There is still time to vote in support of V Care Foundation's nomination [here](#).**

EUROPE



Dear LCE Members,

I hope you have all been enjoying the summer and will be returning rejuvenated. Since the Prague summit in July, Lymphoma Coalition Europe (LCE) has been taking forward some of the plans and ideas we discussed.

First of all, following the interest and support in setting up a Lymphoma Community Advisory Board (CAB) (see Rob Camp's summit presentation on the [Coalition's YouTube channel](#) for more information), we will shortly be sending out more detail on the next steps. This will include an invite for people to become members of the CAB, with full descriptions of what this involves, the knowledge and expertise required and the support that Lymphoma Coalition Europe will provide. This will be an exciting opportunity to be part of a major new development for the Coalition that will help us influence research, clinical trials and access to treatments so that they are truly in the interests of patients and carers.

Secondly, we have begun work on the *Cutaneous Lymphoma – Spreading the Word* project. Cutaneous/skin lymphoma is a rare, challenging and misunderstood subtype with a range of issues for patients and carers, including difficulties in early and accurate diagnosis, access to appropriate treatments and expertise, and limited information and support services. The *Cutaneous Lymphoma – Spreading the Word* project aims to address these issues in three main ways:

- Bringing together expert, patient-focused information on cutaneous lymphoma drawn from around the world (including the Cutaneous Lymphoma Foundation), which will be adapted for Europe, translated into as many European languages as possible and then made available via our website and directly to member organisations.
- Researching and publishing a European directory of cutaneous lymphoma experts and specialist treatment centres.
- Developing a European database of clinical trials in cutaneous lymphoma, with patient-friendly, lay person summaries.

If all goes according to plan, the new resources should be available to member organisations and patients and carers throughout Europe by early 2019. If the project meets its aims, then this may be a model we can use for other underserved subtypes in the future.

Finally, the start of September sees the congress and conference season begin again in earnest. Lymphoma Coalition Europe will be at the following events, so please get in touch if you're also going to be there:

- ECCO 2018 European Cancer Summit (Vienna, Austria, 7 to 9 September)
- EBMT 14th Educational Course of the Lymphoma Working Party on "The Treatment of Malignant Lymphoma: State of the Art and Role of Stem Cell Transplantation" (Palma de Mallorca, Spain, 26 to 28 September)
- EORTC Cutaneous Lymphoma Group meeting (St Gallen, Switzerland, 27 to 29 September)
- ESMO Annual Congress (Munich, Germany, 19 to 23 October)

Best wishes,
Jonathan

NEWS FROM EUROPE

LCE partners with the EBMT Lymphoma Working Party (LWP)



The [European Society for Blood and Marrow Transplantation](#) (EBMT) is a collaborative peer network of professionals working in the field of clinical bone marrow transplantation and cellular therapy. The [Lymphoma Working Party](#) (LWP), composed of a panel of experts in lymphoma including Hodgkin, diffuse large B-cell, T-cell, mantle cell, follicular and Waldenström Macroglobulinemia, is devoted to advancing research and promoting education regarding the role of stem cell transplantation in the management of patients with lymphoid malignancies. The joint effort of the team has resulted in a very active portfolio of ongoing studies and numerous presentations in international meetings and publications in peer-reviewed journals.

Lymphoma Coalition Europe, as part of the effort to bring the patient voice forward, will join the [14th Educational Course of the Lymphoma Working Party](#) on "Treatment of Malignant Lymphoma: State-of-the-Art and Role of Stem Cell Transplantation". This will provide an opportunity to meet the active members of the Working Party, to explain the objectives of Lymphoma Coalition Europe, and explore avenues for ongoing collaboration. This special session is part of the Open Research Forum, which is focused in ongoing scientific projects and new proposals, a group with whom LCE plans to forge a partnership.

ECCO2018
EUROPEAN CANCER SUMMIT

SAVE THE DATE
7-9 September 2018
Vienna, Austria

The **ECCO 2018 European Cancer Summit**, will be held on 7-9 September 2018 in Vienna, Austria, bringing worldwide leaders from the cancer healthcare, patient advocacy and stakeholder communities together in a unique [multidisciplinary forum](#). Connecting science with real life by driving policy evolution at the highest political level, the Summit will:

- Debate leading-edge ideas on outcomes research, health economics and organisation of cancer care delivery;

LCE IS PROUD OF ITS MEMBERS

A comprehensive patient rehabilitation program



SLOVENSKO ZDRUŽENJE
BOLNIKOV Z LIMFOMOM IN LEVKEMIJO

The Slovenian Association of Patients with Lymphoma and Leukaemia has initiated a comprehensive rehabilitation pilot program for patients with blood cancer. The program, supported by the Ministry of Health, is made up of three key modules that empower patients, help them cope with the healing process, and reduce the chances of complications or eliminate them. Patients gain important knowledge, experience and support from experts to make life easier and better during and after illness. The program includes physical (exercise), psycho-social and nutritional modules. Expert consultants are also available to program users. The program is entered by patients during or after regular hospital treatment at the doctor's appointment or through the program coordinator at the L & L Association.

Kristina Modic, Executive Director of the Association, stressed that the need for this type of program has grown steadily in recent years and that the results of the first group of participants who just finished the 6-month program are excellent. [READ MORE](#)

- Determine consensus resolutions for improving health systems;
- Decide on an action plan for the way forward to ensure ideas translate into policies that will impact daily clinical practice.

Lymphoma Coalition Europe will be represented by Jonathan Pearce, Regional Director, member of the ECCO Patient Advisory Committee 2018.

