LYMPHOMA COALITION

Worldwide network of 69 lymphoma patient organisations from 46 countries acting as a central hub for reliable and current information.

Our Mission



Be the global source for lymphoma facts and statistics



Improve awareness and understanding of lymphomas



Build capacity for new and existing lymphoma groups

Dear LC Members,

What a community we have of hard working patient supporters. We hear from many of you on the work that you do, the patient conferences you host, lobbying for access to care, phone support, inperson support and guidance, producing educational materials, hosting and attending board meetings, advisory boards and scientific meetings where you are asked to speak on behalf of the patient voice.

One such example of this was by Rosmarie Pfau at ICML, she did an excellent job presenting how patients might think and feel around therapies options. Click here to review the presentation.

Charlotte will present something similar to this topic at ESMO early September in Madrid, "What toxicities matter to patients?" It would be great to include your thoughts on this topic so please submit your comments to Charlotte so she might incorporate them into her presentation.



The 2017 World Lymphoma Awareness Day package is in your inbox so please review it and let me know if you have any questions or comments. Thank you to the 22 members who attended the webinar on the social media campaign component. The feedback we received was positive. We are happy as a committee that we are on the right track.

The poster component was emailed to you on the 18th please look for it. Plan to be a part of the trending hashtag, #EverythingChanges. We want it to be one of the highest in September!

#EverythingChanges

We want you to influence the **2018 Global Patient Survey** and invite you to be part of the planning committee. Thank you for your time and collaboration, it takes a team to have all the right input.

Remember to submit your **2017 Global Summit** paperwork to Kim by the end of the week. We hope you can join us for the 15th year celebration of Lymphoma Coalition that will be held on December 6 & 7, pre-ASH in Atlanta, Georgia. Submit older pictures and anything that you think might be fun to look back on while we share our history.

If you are a resident of a country that has been blocked from entering the United States, please contact me right away so we can deal with any issues early on.

If this is the time of year that you take a seasonal break we wish you rest and rejuvenation. Turn off your phones and computers. Your emails will wait, your health will not.

Warm regards,

Kaun

Karen

MAINTENANCE THERAPY IN MANTLE CELL LYMPHOMA

The goals of maintenance therapy for the treatment of patients with mantle cell lymphoma, as well as strategies and upcoming research in this setting.

Watch the video here.

PHASE II STUDY OF PEMBROLIZUMAB FOR RELAPSED/REFRACTORY HODGKIN LYMPHOMA

A single-arm phase II study of pembrolizumab in three cohorts of patients with rrHL, defined on the basis of lymphoma progression.

Read more here.

L-MIND STUDY IN R/R DLBCL – TOLERABILITY

Update of toxicity and response rate in Relapse/Refractory Diffuse Large B-Cell Lymphoma in the L-MIND trial presented at Lugano.

Watch the video here.

RESULTS OF THE PHASE III ALCANZA TRIAL

Comparing Brentuximab Vedotin to methotrexate or bexarotene in patients with R/R CD30+ Cutaneous T-Cell Lymphoma.

Read more here.

House 086, China



Welcome House 086, China as the newest member of the Lymphoma Coalition family!

Access Issues to Treatment Centres

Every year, there are nearly 100,000 new lymphoma patients in China. While there are 661 cities, the main treatment centres are located in Beijing, Shanghai and Guangzhou, which are the most developed areas.

"Patients living in these cities will receive better care than those living in more remote areas because doctors in those areas lack experience," said Hong Fei.

Patients can travel to the main centres for treatment but this can be challenging.

Read more here.



Dear Members,

We know for many it is a time to take a summer holiday and reconnect with yourselves, your families and to rest. We wish you a lovely break.

When we return, many of you will be at ESMO, September 8 – IIth and I look forward to seeing you there. As Karen has suggested in her letter, please send me your thoughts on the topic I will present, "What toxicities matter to patients?"

Did you have a chance to review the LCE section of the website! The new LCE information platform dedicated to the most recent information of interest for the European lymphoma community has indeed just been launched - www.lymphomacoalition.org/europe. It is first and foremost a showcase for everything you do for patients in your respective countries. We therefore warmly encourage you to send us pictures of your events; links to the patient education tools you develop; news about the campaigns you promote; and any information you think might be of interest to organisations and patients of other European countries in any language.

Additionally, you will find regular updates on European drug approval decisions; EU regulations, research and projects on lymphoma and CLL and on European Congresses etc. It is also a key instrument to share LCE projects, reports, tools and initiatives with you, as well as with our partners and stakeholders.

Happy summer!

Best Wishes.

Julette

Charlotte

charlotte@lymphomacoalition.org

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EDUCATION SESSIONS: AUGUST - NOVEMBER 2017

Kitchener, Ontario - Peer Support Meeting

08/02/2017

Click here for details.

Germany - Symposium Non-Hodgkin-Lymphome

09/09/2017

Click here for details.

Germany - Freiburger Patientenund Angehörigen-Forum

11/25/2017

Click here for details.

For a full listing of events around the world, see the event calendar on the website. Let us know about your upcoming education programmes so we can promote them.

