

Dear LC members:

It has been a really busy fall!

First, thank you to everyone who participated in World Lymphoma Awareness Day 2019! It was another unparalleled success and the feedback has been great. Watching the digital confidence tree grow during the campaign and reading participants' stories was inspiring. You can find out more information below about this campaign.

Second, it was so good to see many of you in Barcelona at the Global Summit! For those that could not make it this time, we missed you.

At the Summit, the LC Board Chair, Susan Thornton, had the opportunity to present the updated vision, mission and new 5-year strategic plan to attendees. This was the result of much time and effort from the dedicated Board of Directors and LC staff leadership.

The previous vision statement, a world without lymphomas, is something we all hope for, but didn't really express the work of LC. The new vision statement is **equity in lymphoma outcomes across borders**. Equity refers to the fact patients have very different experiences, and despite these differences they all should have the same opportunity for a successful outcome. This new vision better represents what we are all working towards as the Coalition.

The revised mission statement, **enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action**, reflects the need of the entire lymphoma community to

## RESEARCH NEWS

- Relevant biomarkers for the treatment of hematological malignancies [READ MORE](#)
- BTK inhibitors for the treatment of chronic lymphocytic leukemia [READ MORE](#)
- What is the familial risk of developing a hematological malignancy? [READ MORE](#)
- Real-world outcomes with ibrutinib in Waldenström macroglobulinemia [READ MORE](#)
- FCR still an option in IGHV-unmutated CLL? [READ MORE](#)
- Prognostic significance of MYC Rearrangement and Translocation Partner in Diffuse Large B-Cell Lymphoma:

work together to effect positive change locally, that is rooted in credible information.

Much of the new 5-year plan was based on conversations with members through the first part of the year, that included identifying areas of need locally and where help is needed that LC can support. The feedback from the Summit solidified that the plan is moving the Coalition in the right direction. For those that didn't attend the Summit, the 5-year plan presentation and the notes from the table discussions that followed are in the [member's section](#) of the LC website.

If anyone has any questions on the plan, please feel free to reach out to [Susan](#) or one of us.

Best regards,

[Lorna](#), [Natacha](#) and [Pru](#)

A Study by the Lunenburg Lymphoma Biomarker Consortium [READ MORE](#)

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## ASH ABSTRACTS

We are pleased to announce that LC has not one - but two abstracts accepted by the [American Society of Hematology](#):

- *A Cross-Sectional Study Examining the Effects of Patient Information Level on Healthcare Experience in 2 Patient Populations: Extranodal Natural Killer T-Cell Lymphoma (ENKTL) and Waldenstrom Macroglobulinemia (WM)* [READ HERE](#)
- *A Cross-Sectional Study of Unmet Needs of Lymphoma Patients in Patient-Doctor Communication: Follicular Lymphoma (FL) and Diffuse Large B-Cell Lymphoma (DLBCL)* [READ HERE](#)

The abstracts are published in *Blood*, and will be presented by LC at ASH 2019 in December.

Lorna, Natacha and Natalie will be at ASH. Lymphoma Coalition will once again have a booth. If you are attending, please be sure to drop by and say hello.

# WORLD LYMPHOMA AWARENESS DAY 2019

Thank you to everyone who participated in this year's World Lymphoma Awareness Day campaign! WLAD 2019 was an incredible success, seeing participation from around the world from LC members, patients, and the lymphoma community. See below for some impressive results:

- **IMPRESSIONS:** 17.1 million
- **REACH:** 10+ million people worldwide
- **VIDEO VIEWS:** 65,000 ([watch them here](#))
- **TOP HASHTAGS USED:**
  - #WLAD2019
  - #WorldLymphomaAwarenessDay
  - #DíaMundialDelLinfoma

This year's campaign saw the integration of the Confidence Tree - found at [www.worldlymphomaawarenessday.com](http://www.worldlymphomaawarenessday.com) which allowed real-time visualisation of the awareness spread around the globe. Everyone who joined the conversation on WLAD using the designated hashtags had their Facebook, Twitter or Instagram post added to the tree as a leaf. The Confidence Tree grew to over **1,500 leaves** during World Lymphoma Awareness Day!

Check out the [video recap of the World Lymphoma Awareness Day results](#).



Below you will find photos of LC members' events, as well as social media posts from members, patients and supporters.



**Debbie Brown** @bunders74 · Sep 15

A bit of gentle exercise with people (+ a dog) who you love & some sunshine go a long way to helping ease #livingwithlymphoma on #WLAD2019 @LymphomaAction #LiveYourLife #teamlymphoma @knowyournodes #patientadvice



To help with WLAD 2020 planning, please fill out this survey to let us know how your organisation utilised the resources and webinars that LC has created. [Take the survey here.](#)

If you would like to be involved in the planning of WLAD 2020, send [Lorna an email to let us know.](#)

## LC GLOBAL SUMMIT 2019

The 16th Annual Lymphoma Coalition Global Summit was held on 2 & 3 October at the Crowne Plaza, in Barcelona, Spain. There were 41 members from 33 different countries, joined by 13 pharmaceutical partners on day 2, and we thank all who attended.



This year's Summit featured two full-day sessions encompassing presentations on the new LC 5-year plan, key issues like clinical trials and geriatric patients, member activities and best practices, and a number of breakout sessions on important topics like new therapy classes and generating and using data.

As always, hearing from members is an important part of the Summit. Thank you to the following people for sharing with the rest of the group initiatives happening in your local organisations:

- Ropinder Gill from Lymphoma Action shared the history of 3 fundraisers they do, and the lessons learned.
- Monica Pasqualin from ABRALE shared fundraising tips that have been successful for them.
- Jenny Zhang from House086 spoke about their use of data to initiate change.
- Peter Diamond from Leukaemia Foundation Australia shared the results of a new program, Living Well with CLL, created based on patient data, as well as their My Life Counts initiative.
- Lise-Lott Eriksson from Blodcancerförbundet also shared her experience being part of the LCE Community Advisory Board (CAB).

For those of you who were unable to make it to this year's Summit, we missed your presence and hope to see you next time. Speaker presentations, notes from the breakout sessions and photos can be found on the [member's side of the LC website](#) (login required). If you need any assistance with your login information, please contact [Karen Royds](#).

The first day of the Summit concluded with a bus ride up Castell de Montjuïc, to take in some sightseeing, and dinner overlooking the beautiful city of Barcelona. Day 2 concluded the Summit with dinner on the rooftop of the Crowne Plaza where it was announced that [Linfomas Argentina](#) was

awarded the inaugural **Karen Van Rassel Leadership Award** for their outstanding achievements in supporting patients with lymphoma. Congratulations! [Click here to learn more](#) about the Karen Van Rassel Leadership Award.

If you have any more photos you'd like added to the website, please email them to [Karen Royds](#). We look forward to next year's Global Summit!

