

## Our Mission



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



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 an exciting month for the lymphoma community with meetings such as INTERlymph, ICML and EHA. LC attended all three meetings. Shafia interviewed and video-taped 7 researchers from INTERlymph and will be posted to our website by the end of August.

The research being reported at ICML and EHA was really focusing on understanding the biology to the point of creating targeted therapies for our specific classes of subtypes. A good resource for you to get the top updates on ICML and EHA is the Lymphoma Hub website. The KOL interviews are sorted by subtype.



The 2017 World Lymphoma Awareness Day package will be in your inbox so please review it and let me know if you have any questions or comments. It will be a strong social media campaign and we want you to help us have the hashtag, #EverythingChanges trend as one of the highest in September!

The 2018 Global Patient Survey is now in its thinking stage and we would like you to be part of the planning. Please let [Karen](#) know if you would like to be on the planning committee. Thank you for your time and collaboration, it takes a team to have all the right input.

Our hotel is booked for the 2017 Global Summit and those staying for ASH, I am happy to report that we will not have to move hotels this year. Hurray for Kim! The information package will be sent to you over the next couple of weeks. Please mark your calendar and plan to attend the 15th year celebration of Lymphoma Coalition that will be held on December 6 & 7, pre-ASH in Atlanta, Georgia. 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.

Congratulations to Charlotte on the launch of the LCE section of the website. Have a look at it and make sure you send in photos and updates so we can keep it alive.

Thank you for keeping us up to date on your education sessions, conferences and travel. It is great to add it to the calendar of events, post pictures and keep track of all your great work.

Thank you for the work you do every day to support the patients.

What a family we have!

Warm regards,

Karen

### COMBINATION REGIMEN 'VIABLE, EFFECTIVE' FOR FOLLICULAR LYMPHOMA

Jeremy Slade Abramson, MD, provides perspective on the phase 3b MAGNIFY trial presented at the ASCO Annual Meeting.

Watch the video [here](#).

### POORER DLBCL SURVIVAL OUTCOMES LINKED TO DUAL EXPRESSION OF MYC, BCL2

Dual expression of MYC and BCL2 was associated with worse survival among patients with GCB-like DLBCL.

Read more [here](#).

### PROF. MAREK TRNĚŇÝ, CHARLES UNIVERSITY HOSPITAL, PRAGUE, CZ, ON HIGHLIGHTS OF MCL AT ICML 2017

An interview from the International Conference on Malignant Lymphoma June 14-17, 2017 in Lugano, Switzerland

Watch the video [here](#).



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## Soutien et Information Leucémie Lymphoïde Chronique (SILLC), France



AI DE SOUTIEN INFORMATION

Just after the millennium, Christian Puppinc, the president of Soutien et Information Leucémie Lymphoïde Chronique (SILLC), received a diagnosis of chronic lymphocytic leukaemia (CLL) and wanted to find out more about his cancer.

“Even though he was a clinician, Christian could not find any relevant information,” said Pierre Aumont, who is in charge of international relations at SILLC. As a result, Christian along with two or three other patients, one of whom had Waldenström’s macroglobulinaemia (WM), formed SILLC in 2007. They thought it was important to provide help, support and information to patients with these rare cancers. SILLC is based in Paris, France, but has representatives in the different regions of France. Today, SILLC has 2,500 members.

Pierre joined SILLC in 2016.

“I met Christian at my place of work where he was the company doctor. As I was retiring, I had already told Christian I had CLL. He asked me to join SILLC even though I was not knowledgeable about CLL,” said Pierre who has early-stage CLL and has not yet undergone any treatment. Given Pierre’s experience with international business in his work with an energy company, Christian felt that this could be of help to SILLC.

“Christian wanted SILLC to have a more global presence so needed someone who could work at the international level as that is where many decisions are made. He also wanted someone who be aware of what is happening at the regional level especially when it applies to patients,” he said.

### Opportunities for Expanding SILLC’s Presence

During the year that Pierre has been at SILLC, he has identified a number of opportunities for increasing SILLC’s presence.

“I’ve met other CLL patient advocates and members from other associations and we decided to create a global network which is the CLL Advocates Network, (CLLAN),” he said. Pierre is the vice chair of CLLAN’s steering committee. Formed in 2016, CLLAN has already had one meeting that

took place in Belgrade, Serbia, in November 2016.

SILLC also became a member of EURODIS, the rare diseases group in Europe.

“I have been elected as a patient advocate and am a member of a subgroup that focuses on haematology diseases. Our goal is to introduce the patient voice in decision making in Europe,” Pierre said.

In March 2017, SILLC joined the Lymphoma Coalition (LC).

“I think that CLLAN and LC are complementary because CLLAN focuses on one subtype within the family of lymphomas and does not yet have a great deal of experience as it only launched a year ago; whereas LC has a wider focus and a great deal of experience,” he said.

### SILLC’s Objective

The main objective of SILLC is to inform and support patients who have either CLL or WM.

“We provide support and information but no diagnostics,” said Pierre.

SILLC also plays a role in lobbying.

“SILLC is trying to be involved at the different levels of decision making that will have an impact on patients. So, we meet regularly with the different health authorities as well as industry as we need to better understand the evolution of treatments,” he said.

SILLC has no staff. All work is done on a volunteer basis by a board of directors comprising nine people. Among other tasks that the board undertakes are the management of the website, moderating the online forum, and monitoring and updating information on CLL and WM. In addition to the board of directors, SILLC has seven regional delegates, a six-member scientific committee whose role is to follow new developments and a four-member ethics committee to ensure SILLC follows the rules.

Read more [here](#).



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Dear Members,

EHA 2017 Congress is just over and we already miss Madrid with the very hot temperatures. Members from all over Europe attended the event with a guest attendance by Pru who travelled a very long way from New Zealand to join us! Many thanks to Dr. John G. Gribben, EHA new President elect, who made time in his very busy agenda to give us an overview of the [lymphoma and CLL updates at EHA](#). And congratulations to Anita, who remarkably illustrated the patient perspective during the Quality of Life EHA Working Group session.

Many aspects of lymphoma were dealt with during the scientific sessions, from immunotherapy to the new WHO classification of hematologic malignancies that had such a relevant impact on the classification of lymphoma subtypes. We learned about new treatment options, including the first biosimilar of rituximab approved in Europe a few months ago. Pricing of new drugs in haematology and its impact on patient access to treatments were also on the agenda. The meeting was a good place to continue to develop relations with European clinicians, research groups, and with the EHA leadership.

LCE has its own section of the website! The new LCE information platform dedicated to the most recent information of interest for the European lymphoma community has just been launched - [www.lymphomacoalition.org/europe](http://www.lymphomacoalition.org/europe). 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. But 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. We will relay this information through LC social media to make sure the message goes out broadly.

Let's be stronger together.

Best Wishes,



Charlotte

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## EHA Patient Advocacy Booth



## Mrs. Anita Waldmann & Prof. John Gribben



## EDUCATION SESSIONS - JULY 2017

### Portland - CLF-OR Patient Networking Group

07/11/2017

Click [here](#) for details.

### Atlanta - LLS Georgia Blood Cancer Conference

07/22/2017

Click [here](#) for details.

### USA - T-Cell Lymphoma Patient Education Forum

07/29/2017

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.



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