LYMPHOMA COALITION
Worldwide Network of Lymphoma Patient Groups

NODE NEWS | MEMBER NEWSLETTER
January 2017

Our Mission

LYMPHOMA COALITION

Worldwide network of 66 lymphoma patient organisations from 44 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 Coalition Member,

Heading into the new year our heads are full of new possibilities and hopes. It is also a time of overwhelm when we see so much to be done that it all may become daunting. This is the time to ensure you have a plan and you stick to the plan. It makes sense to take time out to create a plan for the year and set your organisational goals if you have not yet done so.

Set daily, weekly and monthly goals and stick to them. Work to accomplish them and when you do celebrate and acknowledge that you did. We often just run to the next thing on the list and miss the great accomplishments to date. Celebrate with your team or your volunteers in little ways along the way so they too will sense the accomplishments.

Undoubtedly there is a lot to do. Never before have we understood the biology of the different lymphomas like we do today. Never have there been so many pharmaceutical companies interested in this cancer and with the cut backs in healthcare and research, scientists are coming together to share information (made easier by technology) and asking patient organisations to work alongside them to better understand the patient experience and share information. These all add to the excitement of possibilities and to the daunting feeling of getting everything done. It is worth it though, every minute of your work. It adds to the larger patient voice and community both locally and globally.

To support your efforts, the Library Resource on the LC website was updated with the latest abstracts and research that was published at the American Society of Hematology conference this past December along with interesting position papers by key opinion leaders. These documents are listed by subtype and you can even search by country.

Interested LC members met on a call this week to offer insight and ideas on WLAD 2017. The theme will be decided by the WLAD member committee when presented with the options at the beginning of February. We will work towards developing program components by mid March. I look forward to a great year ahead leading up to WLAD.

In the meantime continue to use Know Your Subtype as a key message. Encourage doctors and nurses to tell their patients what subtype they are diagnosed with and patients to ask the question of their healthcare team is critical in managing their care.

We wish you great successes in 2017!

Karen.

Take Survey

LC is evaluating the subtype reports and how they are being used and we would like your input. Click on the link below that will take you to a survey that will take no longer than 4 minutes to complete. https://www.surveymonkey.com/r/Subtype_Reports

Please complete the survey before February 11.

If you have any other suggestions and ideas please don't hesitate to email me at shafia@lymphomacoalition.org

FDA APPROVES FIRST-EVER TARGETED MZL TREATMENT

On January 19, 2017, the United States Food and Drug Administration (FDA) approved ibrutinib to treat patients that have received at least one line of prior therapy for marginal zone lymphoma (MZL)...

Read more here.

PHASE 3 STUDY PROMISE WITH OBINUTUZUMAB

Results from a study show obinutuzumab-based immunochemotherapy and maintenance resulted in a significant improvement in progression-free survival compared with rituximab therapy...

Read more here.

TRANSPLANTS WITH CELL MUTATIONS RAISE RISK OF SECONDARY CANCERS

According to a study, lymphoma patients receiving transplant treatment with their own blood stem cells may be at risk of developing another blood cancer...

Read more here.

Leukaemia CARE

(United Kingdom)

Leukaemia CARE, UK, was initially set up in 1967 as an informal support group started by parents with children in whom leukaemia had been diagnosed.

"A group of parents got together around a kitchen table to help each other prepare for, or come to terms with, the death of a child as, at that time, a leukaemia diagnosis would often result in death," said Zack Pemberton-Whiteley, Head of Campaigns and Advocacy at Leukaemia CARE.

In 1969, Leukaemia CARE was registered as a charity. In the 1980s, Leukaemia CARE grew from providing support for those with childhood leukaemia to encompass all forms of leukaemia, in all age groups. Later in the 1980s, the organisation expanded again to provide support for all blood cancers and other blood disorders, as there was not a lot of support available.

"This has now changed, particularly with the presence of the Lymphoma Association in the UK. Where possible, we work together so as not to duplicate efforts," he said.

Zack is one of 20 people on staff at Leukaemia CARE. Prior to joining the organisation in 2014, he had just completed a law degree.

"I saw the word 'advocacy' and liked the idea of representing people who did not have a voice or who, through not understanding the process, might lose out," he said.

Leukaemia CARE approaches advocacy both in their broader policy work and, at the same time, supports individual cases as both are necessary.

Focus of Leukaemia Care

The primary focus of Leukaemia CARE is the support of anyone affected by a blood cancer, ensuring that they receive the right information, advice and support.

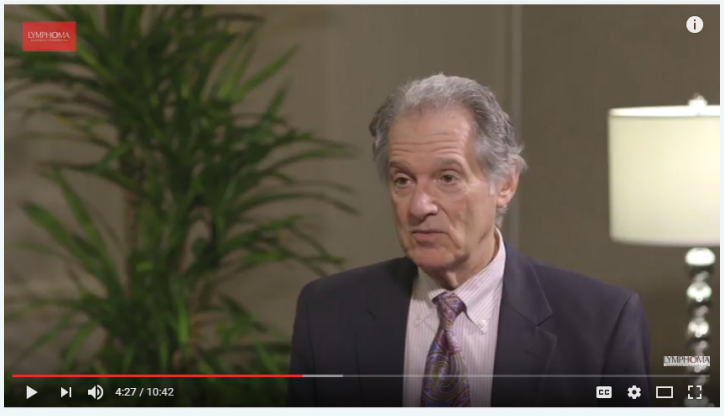
"Predominantly, it is patients and carers looking for support but it includes all family members and friends." said Zack.

Leukaemia CARE provides support for all blood cancers, including lymphoma.

"When Leukaemia CARE receive requests for information about lymphoma, we also tell them about the Lymphoma Association, who may be able to provide further support," he said.

Read more here.

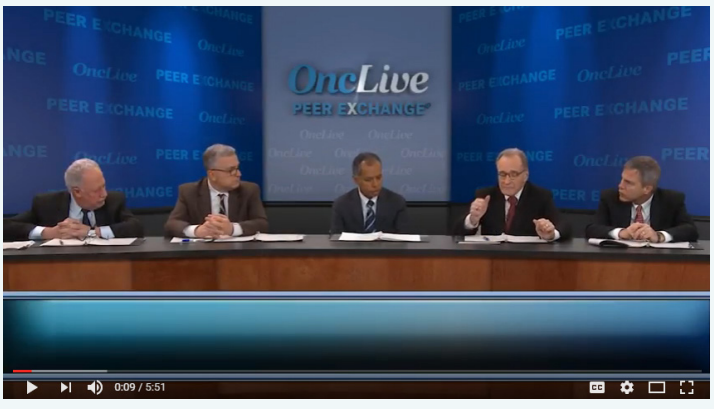
IMMUNOTHERAPY AND LYMPHOMA TREATMENT



Dr. Bruce D. Cheson, MD, DACP, FAAAS, discusses how immunotherapy may replace chemotherapy as an effective treatment for certain types of lymphoma.

Watch the video here.

R2-CHOP FOR RELAPSED FOLLICULAR LYMPHOMA



Panelists Krishna V. Komanduri, MD; John P. Leonard, MD; Leo I. Gordon, MD; and John Byrd, MD, describe the use of the R2-CHOP regimen for relapsed follicular lymphoma.

Watch the video here.

Happy New Year!

LCE started the new year with exciting news. On 16 and 17 January, we took part in the kick-off meeting of HARMONY, a very ambitious five-year EU project funded by the Innovative Medicines Initiative (IMI).

HARMONY aims to foster better access and care for patients with various hematologic malignancies (HMs) - multiple myeloma, AML, ALL, CLL, other lymphomas, MDS and pediatric HMs - creating a big data platform which will integrate outcome measures and endpoint definitions for HMs.

LCE will contribute to HARMONY as an associate partner with the objective to bring lymphoma and CLL patients' experience and perspective forward, and to make sure the research projects it will support serve patients' needs.

The 4th Lymphoma Coalition Europe members' meeting will take place in Madrid on 13 and 14 January. The meeting will last for one and a half days, to allow for more time together for workshops and exchange of good practices.

The programme includes a strong focus on communication and how to adapt your message to the different target audiences and communication channels, in accordance with the wishes you expressed in the interviews last year. Hematologists, nurses, regulators and the industry will also participate in the meeting to discuss patient information and support, with the objective to improve mutual understanding and cooperation.

The communication highlight also encompasses the setting up of advocacy strategies aimed at influencing HTA processes, even when no institutional participation channels exist.

All practical information regarding travel, accommodation and meeting details have been sent to you by e-mail, together with the draft programme.

If you did not receive them yet, please contact me charlotte@lymphomacoalition.org right away.

I look forward seeing all of you in Madrid.

Charlotte

Charlotte

EDUCATION SESSIONS - FEBRUARY 2017

National Lymphoma Telephone Forum
Australia - 02/11/2017
Click here for details.

Conference of Skin Lymphoma Patients - Israel
02/2/2017 - 02/12/2017
Click here for details.

World Cancer Day
Global
02/04/2017
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.