

# YEAR IN REVIEW FY2021

1 APRIL 2020 -  
31 MARCH 2021



LYMPHOMA  
COALITION  
EUROPE



# ABOUT LYMPHOMA COALITION EUROPE (LCE)

Lymphoma Coalition Europe (LCE) is an umbrella organisation of lymphoma member organisations working across Europe. It is a regional branch of Lymphoma Coalition (a worldwide network of lymphoma patient organisations, registered under Canadian law in Mississauga, Ontario, Canada) with a principal place of business registered in Paris, France, under French law. The Lymphoma Coalition's Board of Directors provides governance for LCE's work across Europe, with one Board member nominated to provide oversight of LCE's activities. Currently, Sarper Diler, Secretary, is the nominated Board member.

In its role as an umbrella organisation, LCE has a membership of over 40 national and regional patient organisations from more than 30 countries in Europe, plus Turkey and Israel, which are supported by LCE's work and initiatives.

## VISION

Equity in lymphoma outcomes across borders.

## MISSION

Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.



LCE members are advocacy organisations that all provide support to patients with lymphomas, including CLL.

Through joining LCE, they are part of a Europe-wide network of specialist organisations that provide mutual support and information-sharing to each other, as well as collaborating on regional issues wherever possible.

**OVER 40  
MEMBER  
ORGANISATIONS  
IN MORE THAN  
30 COUNTRIES**

### **FINDING NEW WAYS TO CONNECT & ENGAGE**

The Covid-19 pandemic meant learning new ways to connect, engage, and maintain the vibrant community that has been built and nurtured over the years. Best practices were employed to avoid 'Zoom fatigue' and new types of education were added to minimise impact on people's time.



# MEMBER MEETING

LCE usually brings together a representative from each of its member organisations once a year for shared learnings, discussions and best practice case studies. In FY21, the meeting pivoted to a virtual format due to the pandemic, held over the week of 5-9 October. This allowed more people from each member group to participate, and translation of presentations. 50 people from LCE member organisations attended.



The agenda for the LCE meeting included:

- The impact of Covid-19 on member organisations
- COVID-19 Impact: Building a Virtual Village
- Sustainability: Planning for the Future
- Updates on LCE activities and best way forward
- The Importance of data

Best practice included:

- Transitioning to virtual events, by Stephen Scowcroft, Lymphoma Action (UK)
- How to manage crises communications with patients, HCPs and government, by Berardino Porfirio, AIL (Italy)

Medical sessions included:

Impact of Covid-19 on clinical practice by Prof John Gribben

The impact of Covid-19 on clinical trials by Prof Martin Dreyling



# Congratulations!

Lymphoma Coalition was pleased to present the 2020 Karen Van Rassel Leadership Award to the Lymphoma Patient Association/Udruženje Obolelih Od Limfoma (LIPA) in Serbia.

Innovation, integrity, and responsibility are in the heart of LIPA's work and their collaborative mindset focuses on contributing to better care of patients and their family members. LIPA's ambition is to be the most collaborative and trusted patient organization in Serbia and broader, with a strategy built sourcing for shared value, innovating responsibly, and acting for patients. LIPA had an extraordinary year and was able to drive real change for people affected by lymphoma in Serbia, despite the impact of the COVID-19 pandemic. This was all done by a small team of very dedicated volunteers.

In addition to their robust offering of educational and support sessions in place for those affected by lymphomas, including CLL, LIPA dedicates time and resources to ensuring patients have access to the best therapies. While Serbia guarantees universal healthcare coverage through compulsory health insurance, in reality, there are numerous obstacles in providing healthcare services. In conjunction with the Serbian Hematology Association, LIPA met with government officials and were able to have a special access scheme for novel therapies introduced into the country, allowing more patients access to much needed newer treatments. This is a remarkable end result and an excellent example of how different members of the lymphoma community working together can bring about much needed change.

This is only a sampling of LIPA's efforts. It clearly shows that a small group of committed people can have a large impact, even in challenging circumstances.

To learn more about LIPA's work, visit their [website](#), [educational resources](#) and [app](#).

More information on the Karen Van Rassel Leadership Award is available at <https://lymphomacoalition.org/karen-van-rassel-leadership-award/>.

# LYMPHOMA & CLL COMMUNITY ADVISORY BOARD (CAB)

LCE was able to continue with the Lymphoma & CLL Community Advisory Boards (CAB) in a virtual format. The aims of CABs are:

- Influencing the research and development pipeline for lymphoma (including CLL) treatments to better meet the needs of patients and carers.
- Increasing access to, and reimbursement of, lymphoma (including CLL) treatments across Europe.
- Improving awareness and understanding of lymphoma (including CLL).
- Creating a louder voice for the lymphoma and CLL patient community.
- Recruiting training and supporting more patient advocates and experts for individual countries and Europe as a whole.

## VIRTUAL CABS: JUNE 2020, SEPTEMBER 2020, FEBRUARY 2021

The virtual format allowed more CAB members to participate in each meeting, with 20 advocates attending.

Topics discussed included:

1. Impact of Covid-19
2. Access/availability of novel therapies
3. Outcomes, endpoints and patient selection: Update on real world data
4. Patient engagement strategies
5. Understanding patient/caregiver challenges and needs
6. Toxicity/side effect management
7. Unique needs of elderly populations



# WORLD LYMPHOMA AWARENESS DAY

World Lymphoma Awareness Day (WLAD) is held on September 15 every year and is a day dedicated to raising awareness of lymphoma, an increasingly common form of cancer. It is a global initiative hosted by the Lymphoma Coalition. WLAD was initiated in 2004 to raise public awareness of all lymphoma subtypes in terms of symptom recognition, early diagnosis and treatment.

Around the world, more than 735,000 people are diagnosed with lymphoma every year. With this lesser-known type of cancer, patients face a variety of unique challenges and rely on the support of a team of professionals and personal contacts throughout their cancer experience.

For WLAD, the global lymphoma community gave a *World of Thanks* to show gratitude to those that help improve the lives of people living with lymphoma.

Be it medical care, psychosocial support or the help of caring family and friends, there are many people and organisations who play important roles in improving the lives of people living with lymphoma.

This has been especially true during the pandemic.

The campaign was completely virtual, with increased interaction from member groups, healthcare professionals and scientific societies.





# Covid-19 Response

In May and December of 2020, LC membership participated in two surveys alongside member patient organisations of four other global cancer patient coalitions and alliances: Advanced Breast Cancer Global Alliance, World Bladder Cancer Patient Coalition, World Ovarian Cancer Coalition and World Pancreatic Cancer Coalition. Global Colon Cancer Coalition joined in for the second survey.

The overall results of the surveys showed members of LC had all areas of work affected by the pandemic. LCE members represented 60% of the respondents.

## Services

- Seven in ten organisations who provide support services for patients have seen an increase in the number of calls and emails, with an average increase of 49%;
- More than eight in ten organisations have had calls relating to COVID-19, on average 44% of their total call volume;
- Almost all organisations altered their services for people with cancer (99%);
- Most have had to produce new information relating to COVID-19 (74%), half have moved existing services online (52%) and a third developed new services (37%).

## Finances

- Only 7% are confident of their financial position;
- Almost eight in ten are predicting a fall in income over the next twelve months, on average a drop of 43% is expected;
- Every type of fundraising is affected, from grants and major donors to direct mail, online donations, to community fundraising and organisation run events;
- One in five say that drops in income are currently affecting their viability and 48% say this may be the case in the future.

## Operations

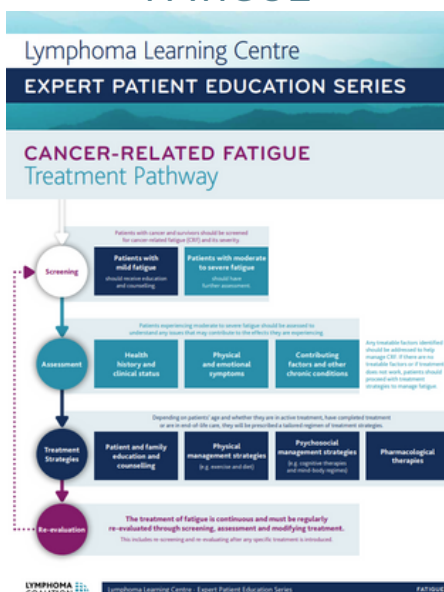
- Almost four in five have already reviewed budgets, with 60% already cutting costs;
- 15% have made staffing cuts;
- One in five have 'furloughed' staff (a government scheme to support staff wages);
- Two in five have had to source technology and equipment to move the working environments into homes and to develop new services.

Find out more at <https://lymphomacoalition.org/covid-19-resources/>.

# TOOLKITS

To support members in their work, LC created two toolkits focused on the leading issues affecting quality of life raised by patients via the Global Patient Survey on Lymphomas and CLL (GPS) - fatigue and fear of recurrence.

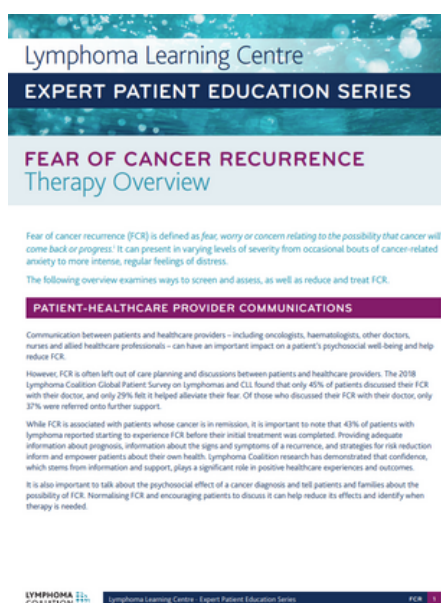
## CANCER-RELATED FATIGUE



Fatigue is the leading physical issue affecting the well-being of patients with lymphoma, and it persists long after treatment is completed. The LC 2018 & the 2020 GPS both indicated that patients are not being educated about fatigue and fatigue management, and the majority are not being referred onto further information and support for their fatigue.

This 10-piece toolkit defines cancer-related fatigue (CRF), has an FAQ sheet, explains CRF clinical practice guidelines, and provides tips for patients on coping with CRF and questions to ask their care team.

## FEAR OF CANCER RECURRENCE



Fear of cancer recurrence (FCR) is a unique and significant mental health issue. It can impact an individual's quality of life and is associated with anxiety, depression and isolation. FCR can also hinder the ability to plan for the future. FCR is the leading psychosocial issue affecting patient wellbeing according to the 2018 & 2020 GPS.

This 10-piece toolkit explains what FCR is, outlines when to seek help (both a patient document and one for healthcare professionals to ensure they recognise the signs of distress), an overview of therapies and other resources that can help, and has questions to ask your medical team.



# SCIENCE

Lymphoma Coalition uses the results from the Global Patient Survey on Lymphomas and CLL (GPS) to conduct and publish its own research on the patient experience.

It is imperative the issues raised globally by patients through the biennial survey are conveyed to the medical and research communities to improve care moving forward.

## EHA CONGRESS 2020

*A Cross-Sectional Study Of Unmet Needs Of Lymphoma Patients In Patient-Doctor Communication.* It was evident that patients who had knowledge surrounding their condition and care plan were more inclined to be confident in taking an active role in managing their health and condition. Access to credible timely information is therefore an important aspect to a successful patient experience. DOI: [10.1182/blood-2020-135837](https://doi.org/10.1182/blood-2020-135837)

## EBMT ANNUAL MEETING 2021

*A Cross-Sectional Study Of The Psychosocial Issues Experienced By Patients With Lymphoma Treated With Stem Cell Transplant.* The treatment and recovery periods for stem cell transplants are complex, and psychosocial assessment and intervention should be a high priority for this population. DOI: [10.13140/RG.2.2.16047.05283](https://doi.org/10.13140/RG.2.2.16047.05283)

## EUROPEAN CAR-T MEETING 2021

*A Comparative Study of Information Needs and Support Experiences of Patients with Lymphoma: CAR-T versus non-CAR-T.* CAR-T patients would like more information and support than what was provided by their doctors. DOI: [10.13140/RG.2.2.10594.45765](https://doi.org/10.13140/RG.2.2.10594.45765)

## EUROPEAN CAR-T MEETING 2021

*A Cross Sectional Study of the Side Effects Profile and Patient Doctor Communication about Side Effects in Patients with Lymphoma treated with CAR T therapy.* Results show CAR-T patients have a higher burden of treatment side effects yet are less likely to communicate all of their side effects experienced to their doctor and a number feel they are not receiving enough help from their doctors in coping with side effects. DOI: [10.13140/RG.2.2.30727.11681](https://doi.org/10.13140/RG.2.2.30727.11681)

Find out more: <https://lymphomacoalition.org/lymphoma-coalition-research/>



# ALLIANCES

LCE collaborates with a number of European patient organisations and networks. Of special note in FY21, LCE partnered with the following:



## EUROPEAN CANCER ORGANIZATION (ECO)

- Created new sub-network focused on the impact of COVID-19 on cancer.

## EUROPEAN COMMISSION

- Feedback provided to Europe's Beating Cancer Plan.

## EUROPEAN HEMATOLOGY ASSOCIATION (EHA)

- Member of European Affairs Committee.
- EHA Board approved the proposal to constitute a formal Patient Advocacy Committee, having a say in all their activities.
- Continue to participate in the group focused on alleviating bureaucracy in clinical research, with participation from EMA, FDA, EC, patient organizations, clinical researchers,
- Contributing to guidelines' discussions, position statements,
- Contribute to the Research Roadmap on Immunotherapy,

## EFPIA: TIME TO PATIENT ACCESS PROJECT

Project focused on recommendations that bring stakeholders in countries across Europe together around opportunities to optimize access to innovative oncology treatments for patients was satisfactorily completed in the spring. The aim was to:

- Apply an unbiased and outside-in perspective
- Ensure an academic basis
- Focus on tangible solutions with impact, that are co-created with all relevant stakeholders.

### EBMT

- Participating in GO CART EBMT Task Force.
- Member of the Patient Advocacy Committee.
- Lymphoma Working Party member.
- Presented in the nurse's program and scientific sessions on patient preference at the joint EBMT/EHA 3rd European CAR T-cell Meeting February 2021,
- Presented on patient preference and the usefulness of Community Advisory Boards perspective at the EBMT annual meeting in March 2021.

### EUROPEAN LYMPHOMA INSTITUTE (ELI)

- LCE participating in a project by providing data to guide the decision making on patient outcomes that should be incorporated as parameters to measure the quality of the lymphoma care.

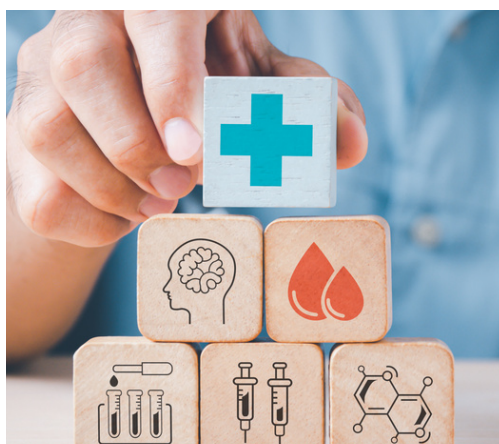
### HARMONY ALLIANCE

As many blood cancers are rare, and healthcare practice varies across the EU, a lack of data on relevant outcomes represents a challenge for clinicians, researchers, and other decision-makers like regulators and HTA bodies, resulting in limitations for patient access to the best healthcare. The HARMONY Alliance aims to use "Big Data and Big Data analytics" to deliver information that will help to improve the care of patients with these diseases.

- LCE is a member of Lymphoma Working Group focused on T Cell Lymphoma and the work party focused on core outcome sets.

### HEMATOLOGY NURSES AND HEALTHCARE PROFESSIONALS GROUP (HNHCP)

- Partnered with HNHCP to create a new Lymphoma Learning Programme for nurses, available online <https://hemcare.org/downloads/lymphoma-program/>



LCE is a branch of the Lymphoma Coalition, with an autonomous budget and a dedicated bank account.

**€134,850**

**FY21 TOTAL REVENUE**

**€91,194**

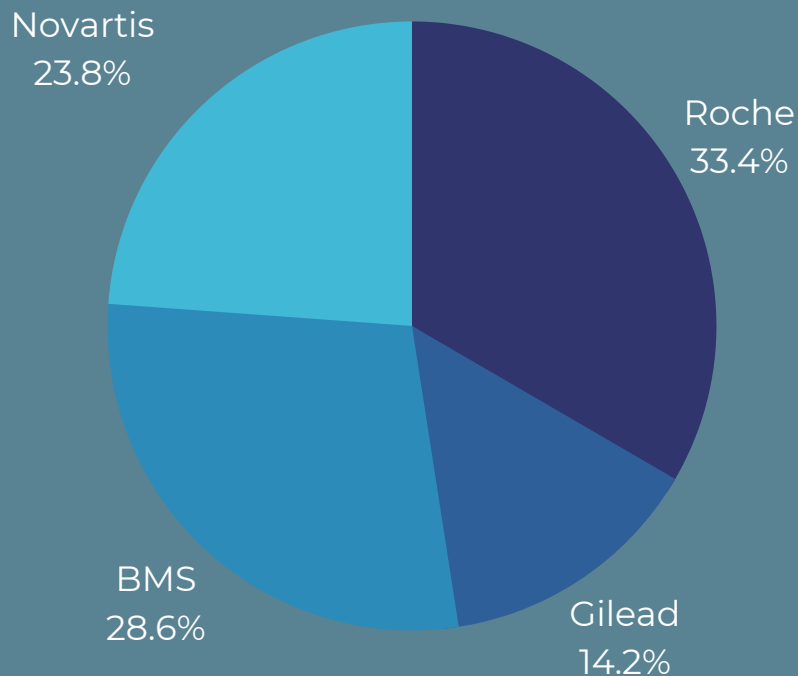
**FY21 TOTAL EXPENSES**

LCE represented 13% of Lymphoma Coalition expenses in FY21. LC and LCE accounts are reviewed on a yearly basis by a statutory auditor.

Audited statements available at <https://lymphomacoalition.org/financials-governance/>



# FY21 LCE Supporters



Thank you to those that sponsored LCE's work in FY20.

LCE's relationships with its sponsors and supporters are regulated by LC policies on Funding Agreements and Transparency.

Find out more at <https://lymphomacoalition.org/financials-governance/transparency-with-corporations-funding-agreements/>





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