

YEAR IN REVIEW FY2020

1 APRIL 2019 -
31 MARCH 2020



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**

WELCOME TO NEW MEMBERS

AELCLES (Spain)

Association of Patients with
Blood Disease Slovenia

See the full list of members
<https://lymphomacoalition.org/member-organisation/#europe>

MEMBER MEETING

LCE brings together a representative from each of its member organisations once a year for shared learnings, discussions and best practice case studies. In FY20, twenty-two (22) members, plus speakers, attended the meeting that was held in Barcelona, Spain as part of the Lymphoma Coalition Global Summit, 2-3 October 2019.

The agenda for the LCE meeting included:

- Overview of LCE activities and engaging members
- Access issues identified in *Lymphoma Care in Europe: Ongoing Exploration of Disparities in Care* report (available here https://lymphomacoalition.org/wp-content/uploads/LymphomaCareInEuropeReport_VF2_A4_Web.pdf)
- Open discussion on how LC can help with advocacy and how members can help each other
- Implementing CAR T cell therapy in the SNS Spain. What lessons we can learn?
- Update on the LCE Community Advisory Board – Lessons learned and next steps

Best practice included:

Non-pharma fundraising, presented by Lymphoma Action CEO Ropinder Gill

Medical sessions included:

Care for Geriatric Patients with Lymphoma, presented by Prof Raúl Cordoba

PRO and QOL Tool Utilisation, presented by Prof Raúl Cordoba

Clinical Trials: Burden and Challenges, presented by Prof John Gribben

The meeting was well received and evaluations indicated members found the content useful.



LYMPHOMA & CLL COMMUNITY ADVISORY BOARD (CAB)

LCE joined forces with EURORDIS (Rare Diseases Europe) to develop a Lymphoma & CLL Community Advisory Board (CAB), with the aims of:

- 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.



SESSION 1: APRIL 2019

Inaugural meeting in Brussels with 14 of the new CAB members for training, as well as patient advocate-led discussions with three pharmaceutical companies.

Topics discussed included:

1. Value
2. Sequencing of treatments
3. Patient education & information
4. Patient-reported outcomes
5. Access/availability of novel therapies
6. Toxicity/side effect management

SESSION 2: OCTOBER 2019

Sixteen advocates participated in the second CAB in Brussels, again taking time for training and discussions with three different pharmaceutical companies,

Topics discussed included:

1. Survivorship & long-term effects
2. Minimal residual disease
3. Methods of therapy administration
4. New therapies
5. Real world data
6. Doctor-patient communication

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.

For World Lymphoma Awareness Day 2019, Lymphoma Coalition (LC) continued the Small Things Build Confidence campaign launched in 2018. Everyone affected by or connected to lymphoma was able to join the global online conversation and share the small things that help them feel more confident.

- LC research has demonstrated that confidence, which stems from information and support, plays a significant role in positive healthcare experiences and outcomes.
- Confidence doesn't always come from one big thing but can be several small things that add up together, leaving a patient feeling more informed, supported and in control.

When we all start bringing the challenges and issues that patients face into the light, we can support them, empower them and help them build confidence.



**WORLD LYMPHOMA
AWARENESS DAY**
15 SEPTEMBER, 2019

Do a **SMALL** thing and
SHARE A FACT
about **LYMPHOMA**
on **social media**.

Every fact shared will grow a
leaf on the Confidence Tree,
building **awareness** and
CONFIDENCE for people
living with lymphoma.

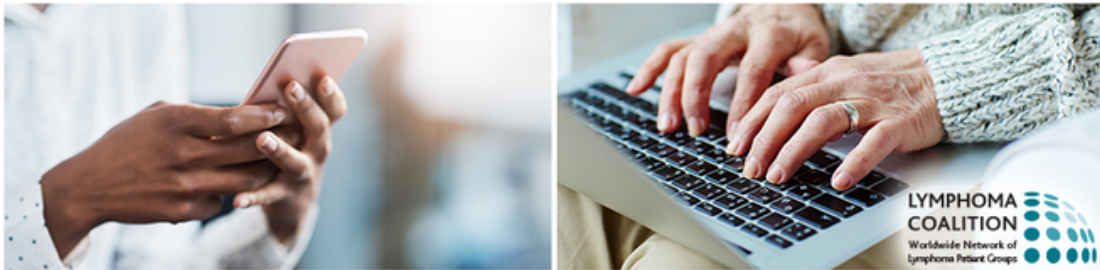
**SMALL
THINGS
BUILD
CONFIDENCE**
#WLAD2019

www.worldlymphomaawarenessday.com

**LEARN MORE &
GET INVOLVED!**

**LYMPHOMA
COALITION**
Worldwide Network of
Lymphoma Patient Groups

2020 Global Patient Survey on Lymphomas & CLL



In 2008, LC launched its first GPS (web-based). It has been conducted every two years since. The survey seeks to understand patient experience in lymphomas as well as the impact of treatment and care. LC and its global members use results to ensure patient voices are heard, to drive planning, actions, and support.

The survey was extensively redeveloped for 2020 and contained both a patient and caregiver version. It was available in 19 languages and was promoted via LC member organisations, scientific partners, community alliances (e.g. HNHCP, EHA, INTERLYMPH), and healthcare professionals, as well as via the LC social media and web properties.

There were 18 countries globally with 100+ responses who received a report on their local data.

This included the following from Europe:

5,067 responses
from Europe
4343 patients
724 caregivers

1. Belgium
2. France
3. Ireland
4. Italy
5. Netherlands
6. Serbia
7. Slovakia
8. Sweden
9. United Kingdom

Read the report here
[https://lymphomacoalition.org/
wp-content/uploads/LC-2020-
GPS-Europe-Report-Final.pdf](https://lymphomacoalition.org/wp-content/uploads/LC-2020-GPS-Europe-Report-Final.pdf)

LYMPHOMA CARE IN EUROPE: ONGOING EXPLORATION OF DISPARITIES IN CARE

LCE publishes a range of reports covering key issues on the diagnosis, treatment and care of lymphomas and CLL in Europe, highlighting gaps or discrepancies in lymphoma healthcare policy and practice and making recommendations for improvement.

LCE publications are aimed at all those with an interest in improving outcomes in lymphoma and can be used by patient/care advocacy organisations to support the case for change in their countries.

Building on the regional findings focused on in 2017, this report looks at the differences between lymphoma care in north, south, east, and west Europe with the following objectives:

- assess changes in incidence and mortality
- identify disparities in treatment and care
- analyse phase II and III clinical trials availability
- report on the patient experience
- identify and make recommendations for future lymphoma advocacy initiatives in Europe.



FOCUS

All patients with lymphoma deserve optimal care. The report Lymphoma Care in Europe: Ongoing Exploration of Disparities in Care demonstrates there are significant disparities across Europe in accessing timely, adequate care.

LC is determined to improve this situation, working alongside other members of the lymphoma community.

The following are identified priorities for the Lymphoma Coalition:

1. STATISTICS

Registries have a critical role, particularly for rare lymphomas. Information garnered from well-functioning registries that integrate patient-reported issues and clinical data can contribute to improved care and improved clinical trial design.

2. CLINICAL PRACTICE GUIDELINES

Evidence-based CPGs must keep pace with regulatory approval of new therapy classes. Many doctors rely on guidelines to understand where a new treatment fits in the treatment paradigm to ensure they are providing optimal care to patients.

3. THERAPY ACCESS

From the information that is publicly available on therapy access, it is apparent that therapies – especially novel treatments – are not uniformly available across Europe. There are pronounced access issues in Eastern Europe, but Western, Southern and Northern Europe also have countries with limited access.

4. CLINICAL TRIALS

Most trials address relapsed/refractory disease, which LC applauds as more treatment options are needed for patients whose lymphoma does not respond to therapy or where the disease returns. It is important that future trials focus on therapies that have minimal or no side effects.

5. FATIGUE

Fatigue is the most reported physical side effect that affects the quality of life for lymphoma patients, regardless of region or subtype. More needs to be done to alleviate the effects of fatigue.

7. INFORMATION

It is critical that patients have access to credible, understandable information throughout their patient experience, but especially in the beginning.



6. BARRIERS IN EASTERN EUROPE

Patients in Eastern Europe report more barriers to care than anywhere else, with financial issues being their primary concern.

8. PSYCHOSOCIAL SUPPORT

The psychosocial impact of the disease must be a focus of care even if it is something as simple as a referral to other places for support. It is important that physicians start the dialogue with patients by asking about their emotional health, let them know concerns like anxiety and fear of cancer recurrence are common and direct to other support when needed.

ALLIANCES

LCE collaborates with a number of European patient organisations and networks. Of special note in FY20, LCE partnered with the following:



EUROPEAN MEDICINE'S AGENCY (EMA)

- Participated in open consultation on the guidelines on quality, non-clinical and clinical requirements for investigational advanced therapy medicinal products in clinical trials.
- Participated in multi-stakeholders workshop entitled “EMA Regulatory Science to 2025”.

EUROPEAN HEMATOLOGY ASSOCIATION (EHA)

- Member of European Affairs Committee.
- Participated in roundtable meeting on bureaucracy in clinical research, with participation from EMA, FDA, EC, patient organisations, clinical researchers.
- LCE supported the test of the HM-PRO tool, promoted by the EHA SWG QOL and Symptoms to prove that is manageable and patient friendly.
- Contributed to the Research Roadmap on Immunotherapy.

EFPIA: TIME TO PATIENT ACCESS PROJECT

Project created to provide unbiased recommendations that bring stakeholders in countries across Europe together around opportunities to optimize access to innovative oncology treatments for cancer patients. The aim is to realize this by:

- Applying an unbiased and outside-in perspective
- Ensuring an academic basis
- Focusing on tangible solutions with impact, that are co-created with all relevant stakeholders.

EBMT

- Member of CAR-T Cell project Governance Structure Working Group, looking at the Cellular Therapy EBMT Registry for CAR T.
- Member of the Patient Advocacy Committee.
- Lymphoma Working Party member.
- Presented patient and patient advocate perspective at the EBMT annual meeting in March 2020.

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.

WECAN (WORKGROUP OF EUROPEAN CANCER PATIENT ADVOCACY NETWORKS)

- The objective of this working group is to collaborate, align and develop joint projects of the European cancer patient community towards all stakeholders, and to provide a resource for the participants and external organisations.



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

€196,791

FY20 TOTAL REVENUE

€209,865

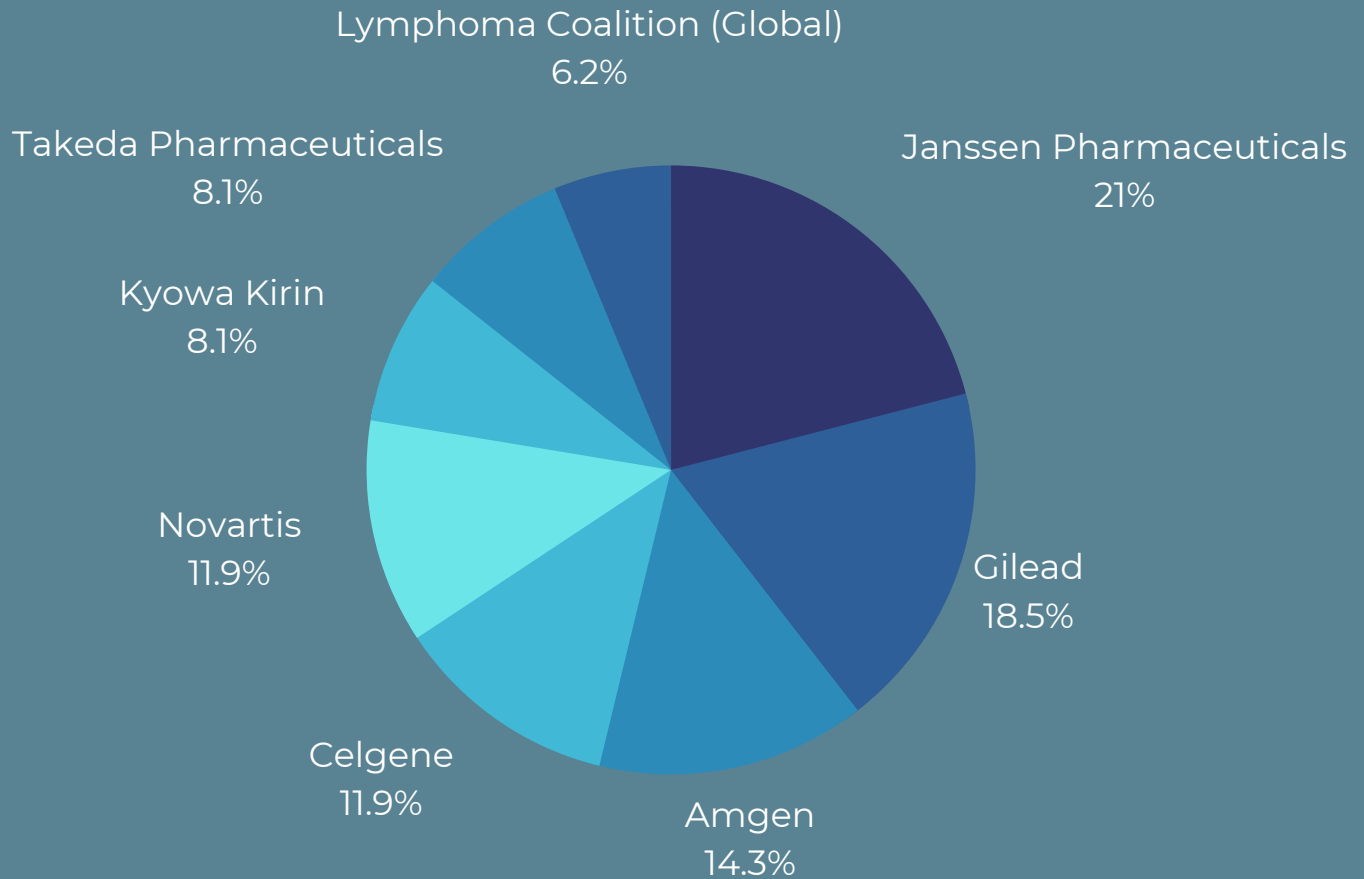
FY20 TOTAL EXPENSES

Funding is supplemented with support from Lymphoma Coalition global revenue.

LCE represented 22% of Lymphoma Coalition expenses in FY20. LC and LCE accounts are reviewed on a yearly basis by a statutory auditor.

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

FY20 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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