



## **LCE's work in Europe and CLL**

**LCE/LyLe National CLL conference**

***Scandic Hotel, Copenhagen***

***Jonathan Pearce, Regional Director Europe – 25 April 2019***

# LCE background and overview

# Vision

LCE's vision is a world in which everyone affected by lymphoma will have access to the best information, support, treatment and care, which is delivered in partnership with respected, valued, well-supported and professional patient/carer organisations in each country.

# Mission

LCE's mission is:

“To improve outcomes for lymphoma by providing credible and reliable knowledge and insight across Europe and harnessing the expertise of individual organisations to bring about systemic change.”

# LCE's overarching objectives

- To be the European source for lymphoma facts, statistics and data.
- To build capacity for new and existing lymphoma groups in Europe.
- To deliver projects and services that bring a tangible benefit to lymphoma patients and carers and the organisations that support them.
- To improve awareness and understanding of lymphoma.
- To improve the lives and outcomes of lymphoma patients and carers through supporting and coordinating effective and influential lobbying and advocacy campaigns.

# LCE's recent work and achievements

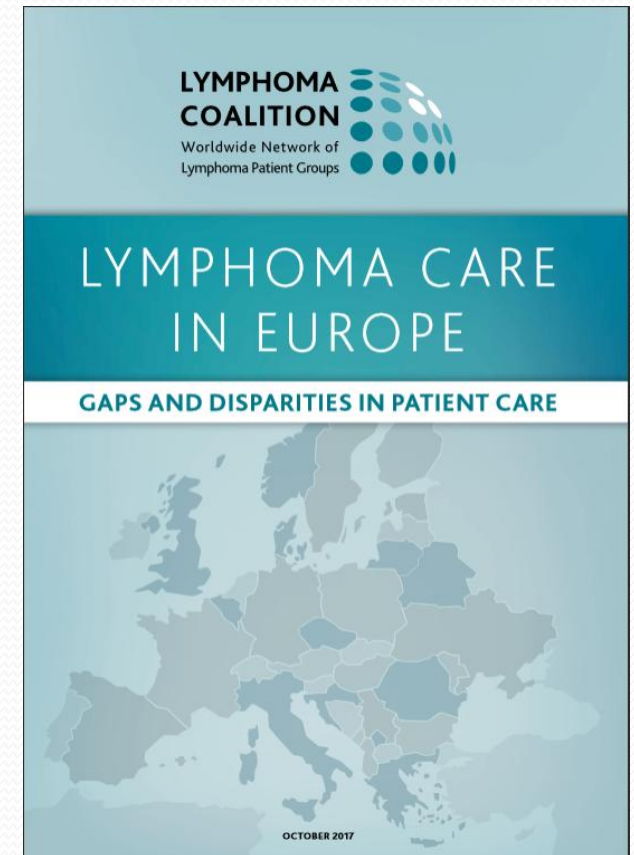
- Secured a place on the European Haematology Association's European Affairs Committee, which has led to LCE coordinating the Advocacy Track at the upcoming EHA Congress in Amsterdam in June 2019.
- Led and supported the development of an NHL research project on the EU-wide HARMONY Big Data for Better Outcomes Innovative Medicines Initiative (<https://www.harmony-alliance.eu/>)
- Recruited and set up a European Lymphoma and CLL Community Advisory Board (CAB) – first meeting held with three companies in Brussels in early April 2019.
- Major 31 language translation project on patient information for Cutaneous Lymphoma.
- Successful regional/global summit for member organisations in Prague in July 2018.
- Supporting this conference.

# Lymphoma Care in Europe (focusing on CLL)

# Lymphoma Care in Europe report 2019

(forthcoming, May 2019)

- Original report published in October 2017; new version due next month.
- Focuses on clinical trials, treatment access and patient experience in six lymphoma subtypes (HL, FL, DLBCL, CLL, MCL and WM) and selected countries in the European region – all as a means of providing a focused representation of the main areas that need addressing in lymphoma diagnosis, treatment and care in Europe.
- Following slides concentrate on some of the CLL points.





# CLL therapy access in Europe

Therapy Access By Country for CLL														
	Novel Therapies										Standard Therapies			
	Bendamustine+ Ofatumumab	FCO	IBR	Ibrutinib	Idelalisib+ Ofatumumab	Idelalisib+ Rituximab	Obinutuzumab + Chlorambucil	Ofatumumab	Ofatumumab+ Chlorambucil	Venetoclax	Bendamustine + Rituximab	FCR	Biosimilar Truxima	Biosimila r
<b>Western Europe</b>														
Austria														
Belgium														
France														
Germany														
Netherlands														
Switzerland														
United Kingdom														
<b>Eastern Europe</b>														
Bulgaria														
Czech Republic														
Hungary														
Poland														
Romania														
Turkey														
<b>Northern Europe</b>														
Denmark														
Finland														
Lithuania														
Norway														
Sweden														
<b>Southern Europe</b>														
Greece														
Italy														
Portugal														
Spain														
Israel														

Data as of November 2018

FCO = fludarabine,  
cyclophosphamide,  
ofatumumab;

FCR = fludarabine,  
cyclophosphamide, rituximab;

IBR = Ibrutinib, bendamustine,  
rituximab

**GREEN** Defined as therapy available to patients through public healthcare

**YELLOW** Therapy available through a special access programme within that country

**RED** Therapy not available/no evidence found

**WHITE** No information found on therapy availability

# CLL therapy access in Europe

- Compared with the other subtypes, CLL had the most treatment options using a novel therapy.
- In Western Europe, Germany was the only country to have all 10 novel therapies accessible to patients through public healthcare.
- All countries had public access to at least one of the two biosimilars listed.
- In Eastern Europe, Bulgaria and Romania had public access to five of the 10 novel therapies listed.
- Sweden was the only country in Northern Europe with access to all the novel therapies listed, while Lithuania had access to only two.

# CLL clinical trials in Europe

- Disproportionate number of trials by country within Europe – many concentrated in Western Europe.
- Seemingly no or little relevance to population sizes or levels of incidence/prevalence of particular lymphoma subtype.
- Northern Europe – Sweden involved in the highest number of novel therapy trials (n=33), and Denmark in 24, while Lithuania was involved in only one which was looking at both FL and WM.
- Same story with CLL trials.

Country	Total Phase 2 and Phase 3 trials	Novel Therapy Trials	CLL Novel Therapy Trials (n=50)
Western Europe			
Austria	35	33	12
Belgium	73	70	17
France	115	106	17
Germany	120	99	28
Netherlands	42	39	7
Switzerland	19	19	4
UK	102	91	25
Eastern Europe			
Bulgaria	14	12	2
Croatia	7	5	2
Czech Republic	49	41	9
Hungary	30	28	7
Poland	67	60	17
Romania	11	9	3
Turkey	26	24	7
Northern Europe			
Denmark	27	24	9
Finland	12	10	2
Lithuania	1	1	0
Norway	15	14	1
Sweden	37	33	11
Southern Europe			
Greece	19	17	3
Italy	119	97	21
Portugal	16	15	5
Spain	97	88	19

Major CLL trials by country	CLL (n=5)
Western Europe	
Austria	0
Belgium	5
France	4
Germany	2
Netherlands	3
Switzerland	1
UK	4
Eastern Europe	
Bulgaria	0
Czech Republic	3
Hungary	2
Poland	3
Romania	0
Turkey	2
Northern Europe	
Denmark	3
Finland	1
Lithuania	0
Norway	0
Sweden	4
Southern Europe	
Greece	0
Italy	3
Portugal	0
Spain	4

# Global patient survey (CLL patient experience in Europe)

- Total number of respondents in Europe: 1630 (including 177 CLL patients).
- While the initial understanding of diagnosis was good or very good in all regions among 50% or more of respondents, the understanding of subtype characteristics was not, with less than 40% of respondents indicating they had a good or very good understanding of their subtype's characteristics.
- Physical side effects of most concern to CLL patients: fatigue, night sweats and changes in sleep patterns.
- The three main psychosocial concerns for CLL patients were: depression, changes in social relationships and anxiety.
- Fear of relapse was of less concern for CLL patients compared to the other lymphoma subtypes that were looked at.

# Questions

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