

Lymphoma Community Advisory Board

Role of CAB member and how to apply to join

Introduction

Lymphoma Coalition Europe (LCE) is working with EURORDIS (Rare Diseases Europe) to set up a Lymphoma Community Advisory Board (CAB). This is an important initiative for LCE and for people affected by lymphoma (including chronic lymphocytic leukaemia (CLL)) both in Europe and globally. The Lymphoma CAB offers the following opportunities:

- To influence the research and development pipeline for lymphoma (including CLL) treatments so that it better meets the needs of patients and carers.
- To increase access to, and reimbursement of, lymphoma (including CLL) treatments across Europe.
- To improve awareness and understanding of lymphoma and CLL, both nationally and across Europe, within the healthcare system, academia, industry and EU institutions, and among the general public.
- To create a louder voice for the lymphoma and CLL patient community.
- To recruit, train and support more patient advocates and experts to work within individual European countries and across the region.

The Lymphoma CAB will be a group of patient advocates and expert patients/carers who use their professional and/or personal knowledge and expertise to discuss and advise on the latest developments, challenges and issues related to medical treatments and procedures under development in their disease area. The CAB will act as a consulting service to stakeholders involved in the research, development, reimbursement and service provision of biomedical treatments or processes, including both scientific and policy-related issues.

This document sets out what is involved with being a member of the Community Advisory Board and related requirements.

Role description

Overview of role

CAB members act as a systematic, efficient, professional and accountable group of collaborators who speak with external stakeholders involved in research and development of lymphoma (including CLL) medical treatments and procedures, including with those involved in the design and running of clinical trials, as well as national and European institutions dealing with reimbursement and access issues. CAB members, both individually and collectively, provide expert advice and insight in a neutral, objective and critically constructive manner, representing the unique perspective of the patient voice.

Main responsibilities or tasks

- To attend meetings of the CAB as and when required, both in person and by way of e-meetings or conference calls.
- To be an active participant in CAB meetings, sharing expert insight and advice with the external stakeholders attending the meetings.
- To commit to ongoing learning, training and development outside of CAB meetings so as to be part of a high quality, well-informed, influential and insightful advisory group.
- To represent the interests of participants in clinical trials, including:
 - Reviewing clinical trial design at a planning stage.
 - Monitoring selected on-going trials with regard to patient priorities.
 - Staying informed about the interim results of selected trials, when appropriate.

- Suggesting and helping start trials that reflect patient needs, and quality of life (QoL) and patient-reported outcome (PRO) measures.
- Reviewing informed consent forms (in relation to appropriate content, language, logic, etc.).
- To promote best practice in research procedures and ethics.
- To represent the patient perspective at investigator and advisory meetings and Data and Safety Monitoring Committees (DSMCs).
- To advocate for fair, sustainable, and affordable pricing and access to treatment.
- To promote universal access to treatment, including for vulnerable groups.
- To support the involvement of patients in adverse events reporting.
- To maintain strict confidentiality in relation to the CAB's work and any information, market insight or personal information shared with the CAB, unless otherwise cleared by the Chairs or Scientific Leads of the CAB.

Reimbursement/remuneration

CAB members will be paid for their time in attending formal meetings at a proposed rate of €400 per day (or part thereof) (subject to funding). Time spent travelling will not be reimbursed, however, reasonable travel and accommodation costs will be reimbursed as per LCE's standard organisational policy.

Key experience, knowledge, abilities and skills

- Excellent knowledge of lymphoma (including CLL) gained from personal or professional experience.
- Good communication and personal interaction skills.
- Good advocacy skills.
- Ability to understand complex science, clinical trials processes and research/development issues.
- Ability to think, communicate and act objectively and constructively.
- Respect for others and integrity.
- A passion for improving outcomes in lymphoma and CLL.

Eligibility to become a CAB member

- 1 To be a Lymphoma CAB member, you must
 - a) be a resident of a European country who:
 - i) has, or has previously been diagnosed with, lymphoma or CLL; or
 - ii) is or was a parent of a child living with lymphoma, or
 - iii) is or was a carer of a person with lymphoma or CLL, or
 - iv) is a family member of a person with lymphoma or CLL, or
 - v) is a member of an organisation working primarily in the field of lymphoma or CLL (see also para 2 below).
 - b) be able to demonstrate a strong interest in the wider lymphoma community and/or lymphoma and CLL treatment research and development, e.g., through being linked with, affiliated to or a member of an organisation working primarily in the field of lymphoma, or through being part of established online social networks related to lymphoma.
 - c) have good English skills, including reading, writing and conversing/interacting in the language.
 - d) be able to demonstrate an interest in, or willingness to learn about, science and medicine in order to fully appreciate the depth of the CAB's work. An interest in social sciences can also be important. (For those with limited scientific or medical knowledge/understanding,

- training and support will be provided, including through face-to-face and virtual training, and through access to past presentations and online/distance learning provided by EURORDIS, EUPATI and Lymphoma Coalition Europe.)
- e) have the available time to commit to the work of the CAB, including any required training. The time commitment varies from week to week, and month to month, but on average CAB members should allow up to eight hours per month.
 - f) have a willingness to travel to CAB meeting, which may be held anywhere in Europe and can last for two, three or four days.
 - g) have a good internet connection to enable e-communication and e-meetings of the CAB.
- 2 If you are applying as a member of an organisation working primarily in the field of lymphoma and/or CLL, please ensure:
- a) You have the permission of the authorised person within your organisation to apply and be part of the CAB, including making the necessary time commitment.
 - b) Your organisation adheres to the [Code of Practice Guiding the Relations between Patient Organisations and the Healthcare Industry](#) (signed by organisations that are members of the Patients' and Consumers' Working Party at EMA) (see attached).

Please note that CAB members take on their CAB roles in a personal capacity on behalf of the CAB, even though they may be applying as a member of an organisation working in the field of lymphoma and/or CLL. However, CAB members can choose to have their fees and expenses reimbursed to either themselves or their related lymphoma/CLL organisation, subject to the agreement they have reached with their organisation.

How to apply to become a Lymphoma CAB member

If you are interested in applying to become a CAB member, please send LCE:

- a copy of your CV; and
- a supporting statement setting out your motivation to be a CAB member and how you fit the above criteria.

Your CV and supporting statement should be sent to:

Jonathan Pearce
Regional Director Europe
Lymphoma Coalition Europe
Email: jonathan@lymphomacoalition.org
Tel: +44 7419 787079

The deadline for applications is **Friday 8 February 2019 at 5.00pm Central European Standard Time.**

If you have any questions or wish to discuss applying, please contact Jonathan Pearce (see above contact details).