

A Community Advisory Board for Lymphoma

Introduction

Lymphoma Coalition Europe (LCE) has agreed to work 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. If successful, a 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 (including 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 rest of this document explains CABs and how they work. For further information, please also see the video and slides of the presentation that was given at LCE's regional summit in July 2018 in Prague, which can be found on the LCE YouTube channel at:

<https://www.youtube.com/watch?v=QKDAxr64yV8>

What is a Community Advisory Board (CAB)?

CABs are groups 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 is established, operated and run by those advocates and experts as a consulting service to stakeholders involved in the research, development, reimbursement and service provision of biomedical treatments, procedures or processes, including both scientific and policy-related issues. The members of the CAB provide their expert advice and insight in a neutral, objective and critically constructive manner, with the CAB operating on an ongoing basis from year to year.

On what subjects or issues do CABs give input?

As noted above, CABs can give advice and input on a wide variety of topics on which they will usually be experts, such as: patient priorities, quality of life issues, treatment side/after effects, patient outreach, education, feedback on clinical trials or research studies and their design, criteria for participation, informed consent forms and processes, compassionate use programmes, retention, and results reporting, and so on.

While each member brings their own personal experience and learning to their role on the CAB, they should also represent the wider community of their disease area. This means knowing about the experiences and perspectives of other patients/carers or groups of patients even if those experiences do not fully match or reflect their own. This is especially important in lymphoma because of the complexity and variety of the 80+ subtypes and variations in diagnosis, treatment and aftercare across Europe.

Who can be a CAB member?

CAB members are people living with the specific condition – in this case lymphoma – or a close family member or carer, and/or a member of a patient organisation that works with the disease. CABs in other diseases areas have anywhere from seven to twenty members. For the Lymphoma CAB, LCE is considering recruiting a larger pool of CAB members – perhaps up to forty people – so that it can ensure a wide representation of lymphoma subtypes and include experience from a lot of different European countries. Subject to interest from potential members and external stakeholders, it may be that more than one Lymphoma CAB is set up, eg., one for indolent lymphomas, and one for aggressive lymphomas. Alternatively, a larger pool of CAB members may be used to establish individual Lymphoma CABs with specific topics or subjects in mind.

How often does a CAB meet and what's involved?

How each CAB operates will vary from one disease area to another. However, it is not uncommon for a CAB to meet maybe twice or even three times a year, depending on stakeholder interest or demand, and the availability of the CAB members. Each CAB meeting may take place over two or more days, depending on the number of stakeholders that are involved and the subjects that need to be discussed. The CAB meetings usually involve an element of training and preparation on the first day ahead of the formal meetings.

Outside of the meetings, CAB members are expected to commit to a programme of learning and training so that they maintain their expertise not only in their disease area, but in the field of relevant research and development and related science. For the Lymphoma CAB, both LCE and EURORDIS would be active in supporting CAB members with an effective learning programme, drawn from their own training resources as well as those of others (eg, EUPATI).

Who pays for the CAB?

The set-up, operation and maintenance costs of the CAB are funded by the external stakeholders (eg, industry, academia, etc) that are interested in seeking the expert advice, insight and consultancy that the CAB members can provide.

Given the time commitment, expertise and expectations involved with being part of the Lymphoma CAB, LCE plans to reimburse members for their time in attending CAB meetings, including reasonable travel and accommodation costs, as per organisational policy.

Does there need to be a CAB in lymphoma?

For most of history, medical science and treatments have evolved with little or no input from the people being studied. CABs can change that and help to design, carry out and communicate on studies that are more rational and inclusive from a patient's point of view. Similarly, CABs can help influence the research and development of medical treatments and procedures, including diagnostic processes and aftercare, so that they focus on the issues that matter most to patients and carers. This is particularly important in lymphoma where patient priorities may change from subtype to subtype (especially between indolent and aggressive forms of the disease) or between different age groups or in different countries.

Furthermore, the level of activity in the lymphoma and CLL research field is one of the highest among all disease areas (not just in cancer) and it is important that there is formalised, organised and coherent patient voice and community that can represent patient and carers collectively across subtypes and across Europe. If the Lymphoma CAB succeeds in its aims, then a bond of trust will be formed with private and public research and development organisations, and national/European institutions, that will help us build ever stronger relationships and achieve greater influence.

Why now?

As noted above, there is such a high level of new research developments in the field of lymphoma and CLL both currently and in future years that a clear, coordinated, coherent and persuasive patient voice is important to ensure new research properly meets the needs of all those affected by lymphoma. In addition, patients and the patient perspective are increasingly seen as a way to make clinical studies have more impact, address inequality and unmet need, possibly be quicker and certainly be more efficient.

How can I join the Lymphoma CAB?

First, please read the other documents relating to the Lymphoma CAB, particularly the role description for being a CAB member and the requirements involved. If you believe you meet all or most of the requirements or are committed to working towards meeting them, please contact LCE:

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