

EpLink Community Advisory Committee

Terms of Reference

Version Number: 0.1

Effective Date: June 24, 2021

Approved by: Joanna Kapusta (CAC Chair) **Date:** June 22, 2021

Reviewers: Joanna Kapusta, Hamed Moazami (EpLink Program Manager)

1.0 Goal: To be a connector between the epilepsy community, EpLink and the Ontario Brain Institute (OBI).

2.0 Objectives

The Advisory Committee will be responsible for:

1. Understanding the goals and objectives of the EpLink research projects;
2. Advising on the direction of the research;
3. Disseminating research information updates to the epilepsy agencies and other stakeholders;
4. Building capacity by linking with EpLink, OBI, industry, and patient groups.

3.0 Composition

At minimum, the Advisory Committee should be comprised of:

- a Chairperson
- persons with epilepsy (i.e., someone <25 years old and someone ≥ 25 years old)
- a family member/caregiver of someone with epilepsy
- a representative from at least three Community Epilepsy Agencies (CEA)
- an OBI representative
- an EpLink Co-Director
- the EpLink Program Manager
- the EpLink Communications Lead
- an EpLink Knowledge Translation Lead
- a healthcare professional (e.g. GP, nurse)

It should be noted that OBI/EpLink/CEA staff hold the seat, not the person.

The Committee should ensure a balanced representation between CEA staff and people with lived experience. Only one representative from each CEA should serve on the Committee.

More than one person from the same family can serve on the Committee.

In cities where there is a DEC/RESC, the CEA representative should be invited to join this committee to allow for community and research synergies (e.g., Ottawa, Kingston and Hamilton).

Should the Chair step down, there will be a nomination phase after which Committee members can vote to elect a new Chair.

A new committee member should be recommended by an existing committee member. A brief summary of why this individual would be a valuable addition to the committee should be sent to the Chair. The Chair will discuss the proposed membership with the committee at the next meeting to determine whether the individual should be invited to join.

