

**CANADIAN LEAGUE AGAINST EPILEPSY/
CANADIAN PAEDIATRIC EPILEPSY NETWORK**

April 15, 2019

*Terms of
Reference*

Background

The Canadian Paediatric Epilepsy Network (CPEN) is a group of Canadian investigators with a special interest in pediatric epilepsy research that spans all four pillars (biomedical, clinical, health systems and services, and population health). Our mission is to promote, facilitate and engage in collaborative research that will advance understanding of pediatric epilepsy, particularly regarding its pathogenesis, causes, natural history, diagnosis, management and its impact on the child and others.

As members of the Canadian League Against Epilepsy (CLAE), a registered Canadian charity, the mission and activities of the CPEN Committee will align with CLAE's charitable purpose:

The mission of the Canadian League Against Epilepsy is to enable Canadians affected by epilepsy to live a life that is not limited by their condition. Our goal is to develop, through research, innovative therapeutic and preventative strategies to avoid the consequences of epilepsy. We also want to translate these discoveries into applicable therapies for all Canadians. Finally, we want to promote national awareness and educate all Canadians about epilepsy and its consequences.

In keeping with this charitable purpose, members of CLAE interested in being involved in a research-based focus on pediatric epilepsy will form the CPEN Committee. The CPEN Committee has the following goals:

1. To facilitate communication among members with similar research interests.
2. To foster research best answered via multi-centre and multidisciplinary collaboration.
3. To promote collaboration with others whose interests overlap with CPEN.

CPEN Executive

The CPEN will be led by an Executive Committee composed of CLAE members and will be governed by the CLAE Board of Directors.

Appointment

The Executive will consist of a Chair or Co-Chairs (either physician and/or a non-physician, or one of each), the immediate past Co-Chair(s), a Secretary/Treasurer and four additional Standing Members (for a total of seven to nine members). These individuals will be identified by a Nominating Committee composed of two prior Co-Chairs (plus one of the current Co-Chairs). Any CPEN member, Executive member or Nominating Committee member can nominate individuals (with their prior permission) or apply for open seats in the Executive (using a standard nomination form). The Executive will ordinarily be multidisciplinary with representation from the different regions of the country. Specifically, the Executive will ideally be composed of members from three geographical regions: (1) West (British Columbia and Alberta); (2) Central (Saskatchewan, Manitoba and Ontario); and (3) East (Quebec and the Atlantic/Maritime Provinces). All Executive members must be actively engaged in pediatric epilepsy research. The Nominating Committee will determine by majority discretion the final slate of candidates to be voted on by the entire CPEN membership. The Executive will then make the final determination based on results of the balloting.

Term

The duration of appointment for all Executive members will be three years with the possibility of renewal for a maximum of one additional term. Terms of Executive members will be staggered as much as possible to ensure

continuity, and each term will commence on January 1st of each calendar year.

Responsibilities

The purpose of the Executive is to enable the goals of the CPEN Committee to be achieved. The Executive will review proposed studies; individual research projects and screening of proposed studies will be administered by the appropriate CPEN investigators.

The responsibilities of the Chair and Secretary are summarized below.

Chair or Co-Chairs

Responsibilities

- Coordinate at least one meeting per year in addition to teleconferences of the Executive committee.
- Prepare meeting agendas.
- Liaise between CPEN, the CLAE board of directors and other research groups.
- Liaise between CPEN, the CLAE board of directors and funding agencies or industry.
- Regularly disseminate information to the CPEN Committee members.
- Welcome new CPEN members upon receipt and approval of an application.

Secretary/Treasurer

The Secretary/Treasurer will be appointed by the current Chair or Co-Chairs.

Responsibilities

- Record votes and minutes of all relevant proceedings (teleconferences and meetings) for distribution to all Executive Committee and CPEN members, as appropriate.
- Distribute proposals and other material to members at the direction of the Co-Chairs.
- Maintain an up-to-date ledger of all CPEN revenues and expenditures. CPEN funds, however, will be housed and expensed through the central CLAE administration.

Full Membership in CPEN

Membership is open to all members of CLAE who have a research interest in pediatric epilepsy.

Application or Nomination for CPEN Membership

A letter of application for membership or nomination, endorsed by at least one current member of CPEN in good standing, should be submitted to the Executive Committee for approval. Upon acceptance as a member of the CPEN Executive Committee, the member shall henceforth be a designated a formal CPEN member.

Membership Dues

All active CPEN members must all also be members of CLAE in good standing (i.e., with annual dues paid). No additional membership fee will be required to join CPEN.

Renewal of CPEN Membership

Membership in CPEN will be renewed yearly upon the member's payment of the annual CLAE dues.

Termination of CPEN Membership

CPEN membership may cease at any time at the request of the member. As noted below, a member may also be obliged to terminate membership for unethical or unprofessional behavior.

Meetings of CPEN Members and the CPEN Executive

- Reports on research projects and budgetary issues will be among the items presented at the CLAE AGM.
- The Executive will meet as needed, either in person or by teleconference, at the discretion of the Co-Chairs.
- All CPEN members are invited to attend general CPEN meetings one to two times a year.

Procedure for Submission of Research Project Proposals

- CPEN Investigators should submit proposals to the Chair or Co-Chairs for distribution to other members of the Executive Committee.
- Executive Committee members will review the proposal(s) and send comments and decisions back to the applicants through the Secretary/Treasurer.
- CPEN Investigators can also nominate other members for receipt and comments regarding proposals.
- The Chair or Co-Chairs will then coordinate a teleconference (if deemed necessary) to discuss the proposal(s) and to formulate responses to the investigators.

Definition of Categories of Investigators

Principal Investigator

- The investigator who has primary responsibility for a research project. This is usually the person who initially conceived of or proposed the project and has contributed significantly to the writing of the proposal and its submission to funding agencies.

Co-Principal Investigator

- An investigator who as judged by other investigators of the group and/or the principal investigator, has:
 - Had consequential responsibility in the intellectual elaboration of a research project.
 - Made a significant contribution to writing a project for submission to funding agencies.
 - Largely contributed to the drafting of an article submitted for publication.

Local Investigator

- The local investigator who assumes primary responsibility for the local implementation of a research protocol in a city or medical center but is not necessarily a PI or Co-PI.

Associate Investigator

- An individual who, as judged by other investigators, has had significant responsibility in the practical realization of some aspects of a study (such as laboratory work, recruitment of patients, etc.) or in the analysis of results, or the critical review of the data.

Credits

- The first three categories of investigators are to be included in lists of authors, in order of significance of contribution (e.g., number of patients enrolled, or other criteria agreed to by the investigators). Associate Investigators are to be included in the credits.

Statement of Ethical Conduct Principles

Working under the governance of the Canadian League Against Epilepsy, CPEN is a collaborative network of investigators who share their intellectual property and resources for the common goal of undertaking and disseminating research in pediatric epilepsy.

To promote the free flow of ideas amongst CPEN members, there must be an expectation of ethical behavior among participants. Collaborative research can only flourish in an atmosphere of openness and trust. This expectation of ethical behavior must extend to the interactions with other groups, funding partners and industry.

Ethical Behavior Among Investigators

The “intellectual property” of a CPEN protocol belongs primarily to the principal investigator(s) and secondarily to the participating investigators.

When a protocol is introduced to the CPEN membership by an investigator through the Executive Committee, other CPEN investigators should declare any real, perceived or potential conflicts of interest and recuse themselves from further discussions of the protocol. Such conflicts include, but are not limited to, developing or implementing, or intending to develop or implement, a similar protocol with the same or other funding agencies outside of the CPEN network.

Once a CPEN investigator has agreed to participate in a particular study, the investigator should not undertake any conflicting study that could interfere with the capability to successfully complete the CPEN study. In the event that a CPEN study does not get implemented, a participating investigator should not undertake a similar study without prior discussion to determine whether the study impinges on the intellectual property of the CPEN study. The preceding statement applies to studies with the same or other funding agencies.

Prior to launching a study, rules of interaction and a delineation of roles/responsibilities should be established amongst investigators. These “rules” should govern the performance of supplementary studies, additional use of clinical material derived from the study, and use of the data (presentation, publication).

Breaches of Ethics by CPEN Members

Allegations of breaches of ethical behavior by any CPEN member will be brought to the CPEN Executive. This process will be strictly confidential. After an investigation into the circumstances of the alleged incident, including written testimony by involved parties, the CPEN Executive will render a judgement. The involved party/parties will be informed of the decision in writing. Sanctions available for breaches of ethical behavior by a CPEN member include a written warning, suspension or termination of membership. An appeals process, if desired by the affected party/parties, can be submitted through the CLAE offices.

Termination of Membership

Termination of Membership for CPEN Committee members will follow CLAE's formal process as outlined in its bylaws under "Termination of Membership".

Management of Funds

Any funds secured for the purpose of supporting CPEN activities will be managed by the CLAE Secretariat. The CPEN Secretary/Treasurer, in conjunction with the CLAE Secretariat, will develop a yearly budget and track all revenue and expenses. An external review by a public accountant will be performed annually as part of the regular year-end financial processes for CLAE in compliance with charity law.

CPEN will be fully responsible for paying all administration expenses for work performed on their behalf by the CLAE Secretariat.

CPEN will be fully responsible for paying for any costs related to CPEN activities, i.e., meetings, venue bookings, catering, telecommunications, etc.