

COMMUNITY ADVISORY COUNCIL

PURPOSE

The Brain Recovery Project dba Pediatric Epilepsy Surgery Alliance's Community Advisory Council (CAC) provides insight on community concerns before and after epilepsy surgery in childhood. It influences the organization's strategic initiatives, web content, guides, biennial conference content, and research by bringing perspectives that can only come from community members.

COMPOSITION

The CAC is comprised of parents/guardians of individuals, and adults, who had epilepsy surgery in childhood. The CAC will consist of 5-20 members who have been invited to serve by the organization's Executive Director.

The CAC is led by the organization's Executive Director.

ELIGIBILITY

Members must be parents or guardians of children (including adult children) who had epilepsy surgery in childhood or adults who had epilepsy surgery in childhood. Members of the CAC must be willing to support and assist with the mission, goals, objectives and values of the organization. Individuals should represent various socio-economic, cultural, racial, surgery, etiology, and functional outcomes backgrounds.

TERM

CAC members will serve for terms of three (3) years. At the end of his/her term, a CAC member may be invited to serve for another term, with no limit to the number of consecutive terms permitted, though rotation of membership is expected. A member of the CAC may resign by submitting a written notice to our Executive Director. The Executive Director may fill a vacancy on the CAC by appointing a new member.

OPERATION

Meetings

CAC meetings will be held four times a year. All meetings may be held in person or by teleconference call, at times and in places determined by the Executive Director. A vote equal to or greater than the majority of members then in office and voting shall be required to carry any motion. Votes may be cast in person, by phone, by fax, by e-mail, or by proxy (if organized in advance).

Compensation

CAC membership is purely voluntary. Members of the CAC will receive no compensation for their time or their expertise. CAC members will be reimbursed, however, for expenses that are incurred in order to fulfill their specific responsibilities to the organization, as long as these expenses are reasonable and appropriate, are authorized by the Executive Director in advance, and are not covered by other means.

Operating Guidelines

These operating guidelines may be changed only by a vote of the Board of Directors, though recommendations for changes will be welcome from the CAC itself.

Roles and Responsibilities

Members of the CAC will give bring community perspectives on the following:

Writings, including web content and printed material, published by The Brain Recovery Project.

Making recommendations to the Executive Director concerning the development and execution of appropriate and effective programs.

Making recommendations to the Executive Director concerning the need for new written

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materials, web content, programs, research, and/or policy statements.

Biennial conference content and planning.

Other similar duties as may be requested by the Executive Director from time to time.

CAC members will:

Allow his/her name to be displayed as a member of PESA's CAC on the organization's letterhead, in various publications, and on the organization's website:

www.epilepsysurgeryalliance.org

Making a concerted effort to attend CAC meetings.

In carrying out these duties, each member of the CAC will be responsible for keeping certain information about the organization's, researchers, grants, and individual patients confidential, as dictated by regulation (e.g., HIPAA) or ethics standards or as requested by PESA.

Approved by the Board of Directors on April 27, 2018.

Edited to include dba Pediatric Epilepsy Surgery Alliance on February 2, 2023.