

YOUNG ADULT ROLE ON CYE ADVISORY COMMITTEE

The Advisory Committee for the National Coordinating Center for Epilepsy (CYE AC), includes health care professionals such as physicians and nurses, non-profit organizations, federal agencies, and other young adults/family members. Together, these representatives help guide the strategic direction of the AAP National Coordinating Center for Epilepsy to improve access to quality health care for CYE across the US. The AAP believes that youth and family engagement in informing strategic direction is critical and greatly values this perspective.

Roles of the Young Adult Advisory Committee Member

- Contribute to the discussions and share experiences and perspectives with the goal of ensuring that patient- and family-engagement is considered in the products being developed.

Term of Office for Young Adult Committee Member

- 2-year term, officially beginning on November 1 and end on October 31. Appointment shall be limited to 2 consecutive 2-year terms for a maximum of 4 years.

Preparation

- AAP staff will provide training and ongoing support in order to ensure the young adult AC member feels comfortable communicating via the CYE AC listserv, contributing to the discussion during meetings, and providing their perspective on development of materials.

Committee Meetings

- Quarterly virtual meetings that last about one hour via Zoom Videoconferencing technology.
- There are typically two, 1-day in-person meetings during the grant year. For those who are unable to participate in person, the option to join the meeting via conference call for all (or a portion) of the meeting may be available.
- **Travel and Related Expenses to Committee Meetings:** Travel costs for all AC members (i.e., airfare, hotel, ground transportation, meals) to attend meetings will be covered by the AAP through expense reimbursement following the meeting. An expense reporting form will be provided to all AC members shortly before or during the meeting in accordance with AAP travel policy. Efforts will be made to minimize up-front out-of-pocket expenses (i.e., airfare and hotel will be charged to AAP master account). When meeting information is sent to all committee meeting attendees, it is expected that all AC members will meet the deadlines set forth to ensure proper meeting planning. Note: the AAP does not pay for, nor reimburse, alcohol purchases.

Communication

- The primary form of communication between AC members and staff is via email. Emails will be sent as information is needed or assignments for review or other activities are identified. Timely response to requests and adherence to deadlines is appreciated.
- As with many committees, much activity occurs outside the in-person meetings. AC members are often emailed documents for review and comment. The young adult AC member is strongly encouraged to review this information and provide feedback/input from their perspective. Please note: **All draft Academy materials are embargoed** and it is the responsibility of the recipient of the draft document to honor the embargo. AC members may author AAP documents.
- At times, AC members may be offered additional opportunities to provide feedback on AAP documents and activities (e.g., policy statements, clinical reports, technical reports, book chapters, web information, documents from other AAP committees/ councils/sections, etc.) that are not primarily sponsored by their committee. Participation in those opportunities is at the discretion of the young adult AC member.
- **Members Only Listserv**
This committee utilizes an email listserv to facilitate electronic communication. All AC members will be added to the committee listserv so that they may stay apprised of activities.

- **Information Sharing and Promotion of Organizational Initiatives**

Young adult AC members are encouraged to share and promote information, new initiatives, new resources, educational opportunities, and other newsworthy announcements that could be of potential interest to AC members and/or AAP members. AC members should share this information with the AAP staff manager for distribution to other AC members via listserv. Additionally, the AAP staff manager can assist in navigating other AAP communication networks channels including, but not limited to an article in the daily email blast to AAP members; communicating with specific committees/councils/sections; an article in *AAP News*.