



Epilepsy Policy Advisory Committee

Role:

The Epilepsy Foundation's Epilepsy Policy Advisory Committee provides input and guidance on the Foundation's advocacy and policy agenda that works to overcome the challenges of living with epilepsy and accelerate therapies to stop seizures, find cures and save lives. Working at the charge of and in coordination with the Foundation's Advocacy team, the Committee advises on various matters including finalization of the Foundation's annual policy agenda and the Foundation's position on new and/or complex policy issues.

Responsibilities:

- Provide input on finalization of the Foundation's annual policy agenda at the federal and state levels;
- Provide perspective and input on the Foundation's position on new and/or complex policy issues;
- Attend and actively participate in an annual meeting to occur in the Fall that finalizes the Foundation's policy agenda for the upcoming year;
- Attend and actively participate in meetings as needed throughout the year;
- Stay informed and engaged on the Foundation's advocacy and policy work through various means including being part of its Speak Up! Speak Out online advocacy network;
- Build relationships with elected officials and represent the Foundation in advancing its policy agenda as needed;
- Be an ambassador of the Foundation's advocacy work, educating others about the Foundation's advocacy and recruiting others to become advocates; and
- Log hours and report advocacy volunteer activities in VolunteerHub on a monthly basis.

Qualifications:

- Passionate about driving systemic change through advocacy; prior government relations or policy experience is not necessary but is beneficial;
- Knowledge of or interest in the Foundation's policy priority issue areas of access to health care, disability rights, research and innovation and funding/appropriations;
- Responsible and accountable;
- Ability to work individually and collaboratively;
- Personal relationship to and/or professional experience with the epilepsies; and



- Age 18+

Membership:

- Total membership size of the Committee should be between 10-15 individuals. The Foundation's Advocacy team members serve as staff coordinators of the Committee and are not included in its membership size.
- Membership consists of diverse, relevant perspectives that have a personal relationship and/or professional experience with the epilepsies. This can include:
 - Individuals living with epilepsy including the rare epilepsies;
 - Family members of people living with the epilepsies;
 - Healthcare providers including epilepsy specialists;
 - Researchers in the epilepsy space; and
 - Relevant Foundation staff including from the research and public health and education teams and from the Foundation's chapter and affiliate network.
- In order to leverage existing Foundation committees and offices, membership shall include:
 - At least 1 member of the Foundation's National Board of Directors;
 - At least 1 member of the Foundation's Professional Advisory Board (PAB); most often, this will be the PAB's Advocacy Committee Chair;
 - At least 1 Foundation chapter representative; and
 - At least 1 Foundation affiliate representative.

Membership Term & Time Commitment:

- Membership: Two-year term with possibility of renewal. Should a Committee position become vacant mid-term, it will remain vacant until the next annual nominations process. Consistent lack of attending the Committee meetings will be a significant factor in renewal of Committee members' terms.
- Time Commitment:
 - Two 1-hour orientation trainings;
 - One 2-3 hour annual meeting held in the Fall to finalize the Foundation's policy priorities for the following year;
 - Ad hoc meetings as needed.

Nominations Process, Trainings & Resources:

- During open nominations periods, Foundation headquarters staff or local office staff must complete and submit a Nominations Form to the Advocacy team for



consideration and selection. A background check will be run on possible candidates. Interviews to be held if necessary.

- If selected to join the Committee, the Foundation will provide two onboarding trainings—one about the Foundation and our volunteer programs generally and one about this specific volunteer role.
- Committee members will be added to the Foundation’s Speak Up, Speak Out! online advocacy network in order to receive monthly advocacy e-newsletters and action alerts on important policy.

To apply: Complete online application at <https://forms.gle/xH2FWGAXRfLZ5PgA7>.