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Charter for Simons Searchlight Community Advisory Committee Version 2.0

Simon Searchlight's Mission

Simons Searchlight is an international research program with the goal of accelerating science and improving lives for people with rare genetic neurodevelopmental disorders.

Purpose of Community Advisory Committee

The purpose of the Community Advisory Committee (CAC) is to advise and guide research and community activities on behalf of all Simons Searchlight participants and genetic communities.

Membership

- The CAC will have up to 20 members.
- Members must be at least 18 years old.
- The Simons Searchlight study team will review membership to be sure that the CAC is representative of the Searchlight community.
- Members will be invited to serve for two-year terms and may resign at any time.
- The participation of members will be reviewed annually and some members may be rotated off of the council if appropriate.
- New members may be added periodically.
- At this time, members must be fluent in English due to the structure of the conference calls and method of disseminating surveys and other information.
- To ensure an equitable rotation of CAC members, we do ask those who have already served two terms to please wait at least two years before applying again. Thank you for understanding.

Responsibilities

- Members of this group will be asked to devote at least 10 hours per year to CAC-related activities (3-hours to Spring and Fall meeting; 7-hours to working group activities). This will be a combination of attending the required virtual meetings as well as completing in-between project assignments through working groups.
- Work with Simons Searchlight staff and contribute to one or more of the following working groups:
 - **Aging Up Resources, Older Adult & Family Support** – Identify and review resources to support older adults and families navigating transitions into adulthood, including topics like menstruation, technology for independence, and access to genetic testing, with a focus on communities of color.
 - **Research Participation & Communications Enhancement** – Improve the research experience by refining the participant dashboard, enhancing automated communications, addressing international family needs, and ensuring accessibility in FAQs, marketing materials, and outreach efforts.

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- **Researcher/Industry-PAG Relationship Development & Outreach** – Expand access to Simons Searchlight data and biospecimens by strengthening connections with researchers, advocacy groups, clinicians, and industry partners. This includes improving data visualization tools, developing plain-language resources, and supporting researcher engagement at conferences.
- Share the outcome of the CAC decisions with their larger family genetic organizations, when applicable.
- Staff will ensure that activities are designed so that members can participate when and where it is most convenient.

Meetings

Two online 90-minute conference meetings will take place biannually in the Spring and Fall. These meetings will be recorded for those who cannot attend at the time of the call but will be required to still provide feedback after the meeting. Staff will convene ad hoc meetings with subgroups of the CAC as needed. Staff will provide all members with an annual report that includes information about how your CAC participation has contributed to Simons Searchlight.

Compensation

Active participants will receive a \$500 honorarium as a thank you for each year of participation (active includes attending two virtual meetings and providing periodic feedback on on-going CAC-related activities).

Liability

Members of the CAC shall not be held liable for any actions taken by them in their capacities as members.