



The cureCADASIL Scientific Advisory Board (SAB) Charter, January 2025

Purpose

Having an active SAB will help cureCADASIL fulfill its mission to advance “CADASIL research through uniting patients, researchers, and clinicians to find a cure for CADASIL.”

The purpose of the SAB is to provide expert guidance and strategic oversight to advance the research mission of cureCADASIL; The SAB will:

- **Guide research strategy and priorities:** Shape the research roadmap by identifying and prioritizing key areas of scientific inquiry aligned with the cureCADASIL mission;
- **Identify research gaps:** Evaluate current research landscape to highlight areas where cureCADASIL and the patient community can have a meaningful impact;
- **Evaluate Biopharma research opportunities:** Contribute to the scientific review of proposals to ensure alignment with cureCADASIL’s goals;
- **Advise on Grant Applications:** Provide scientific review of research grant application, offering insights on the scientific merit and alignment with cureCADASIL research goals;
- **Recommend Therapeutic Approaches:** Suggest innovative methods for discovering and developing potential therapies for CADASIL;
- **Identify Potential Investigators:** Recommend investigators with relevant expertise to explore promising therapeutic approaches;
- **Prioritize Research Initiatives:** Help prioritize research projects based on available resources and current scientific and therapeutic needs;
- **Collaborate to develop patient-centered solutions:** Work jointly with the Board to recommend innovations that prioritize the needs and experiences of CADASIL patients, ensuring the therapeutic advancements align with the lived experience and the unique challenges faced by the patient community.

While the purpose of the cureCADASIL SAB is primarily to benefit the patients and family members that the organization represents, we anticipate that SAB members will also benefit from sharing information and expertise among colleagues. Indeed, it is our hope that this exchange will lead to fruitful research collaborations.

Membership

The SAB will have at least 3 and **up to 9** members, ideally an odd number, and representing diverse backgrounds, expertise, and perspectives. Members may include:

- Eight members with expertise in basic, translational, and clinical research, recognizing that not all expertise will be in CADASIL *per se*, but may be in areas directly or indirectly applicable to CADASIL.
- One member will be a patient with CADASIL. This member does not need to have a scientific background.

Selection Process

The Board of Trustees will be responsible for appointing and replacing members of the SAB, however the Trustees may opt to form a search committee to facilitate this process.

Selection Criteria

- Ability to collaborate effectively in a team setting demonstrated through experience or references
- Diversity of perspective and experiences, ensuring representation from various demographic groups and backgrounds to enrich discussions
- Demonstrated commitment to advancing research in rare disease through previous involvement in patient advocacy, healthcare initiatives or related activities

Term Length

Terms of service on the SAB will be 2 years, with the possibility of serving more than one term.

Members will be asked to declare conflicts of interest annually; A conflict will cause recusal on an issue-to-issue basis, as determined by the Chair.

Roles & Responsibilities

Chairperson

One member of the SAB will serve as the Chair. The SAB Chair will:

- Set SAB agenda with direction from the cureCADASIL Board
- Schedule and facilitate SAB meetings, and ensure productive discussions
- Serve as a non-voting member of the Board of Trustees

Members

Members of the SAB will:

- Attend scheduled meetings, actively participate in discussions and provide honest and constructive feedback
- Respect the confidentiality and privacy of sensitive information shared during meetings

Subcommittees

- The SAB may establish subcommittees to support their duties.
- The SAB chair will provide written determination to the Board of Trustees that a subcommittee will be formed. Appointments to the subcommittees will be made by the Board of Trustees.
- Subcommittees will not work independently of the SAB and will report all their recommendations and advice to the SAB for its thorough deliberation and discussion.
- An appointment to a subcommittee is separate and distinct from an appointment to serve as a member of the SAB. Each subcommittee member is appointed to exercise their best judgment and deliberate in a manner that is free from conflict of interest.
- A subcommittee leader will be selected from the members of the subcommittee.

Meetings

The SAB will meet twice yearly, but more often if needed, especially if urgent matters affecting research priorities arise. Agendas for meetings shall be developed by the chair in collaboration with cureCASADIL

Board and circulated to members at least seven days before the meeting. The Chair will take and distribute minutes to the SAB and Board within 10 days of the meeting.

Board members will not take part in the SAB meetings, unless the SAB invites a member of the Board or its members to provide background information needed for deliberations.

Amendments

Modifications in this charter will be made by a majority vote of the Board of Trustees.