

**Example of email communication for Lived Experience Self-nomination for SEP Review**  
(disease name, FOA title, and due date to be inserted for each use)

Lived Experience Self-nomination for SEP Review of ALS RFA

Dear ALS community members,

The [National Institute of Neurological Disorders and Stroke \(NINDS\)](#) at the National Institutes of Health is seeking self-nominations of persons living with ALS, caregivers for persons with ALS, or persons at risk of developing ALS to serve on a Special Emphasis Panel (SEP) being assembled to review applications responding to the Funding Opportunity Announcement (FOA) [RFA-NS-23-012](#) titled: **Amyotrophic Lateral Sclerosis (ALS) Intermediate Patient Population Expanded Access**. The SEP will meet via a day long videoconference in early May 2023. Some eligibility parameters apply (please see below). Self-nominations from individuals from historically under-represented groups are welcome. Self-nominations are entirely voluntary.

**Qualifications**

Eligible nominees will confirm the statements below:

- I can maintain confidentiality and protect the integrity of the peer review process.
- I can follow instructions and be fair and objective in my evaluations.
- I can clearly and succinctly articulate my views through oral and written communications (use of a proxy and/or accommodations permitted).
- I can be open-minded regarding disparate opinions (consensus while desirable, is not always possible on review panels).
- I have a reasonable command of the English language
- I have a reasonable level of comfort with email and in navigating the internet (downloading and uploading files, filling forms etc.).
- I have an appreciation of the need for clinical trials and protection of research participants in clinical research.
- I am comfortable expressing individual opinion(s) on a panel of clinician scientists and other subject matter experts.
- I am willing to have my name publicly posted on the Scientific Review Group Roster.
- I am available and able to participate in review meetings including possible full days, and/or multiple days via videoconference.

**Selection Process and Training**

NINDS staff will review these self-nominations and make selections from them to ensure a wide diversity of backgrounds and perspectives and based on the context of work to be performed and the ability to execute the responsibilities of the review panel. The Scientific Review Officer may contact short-listed nominees in April by phone or videoconference for final selection before an invitation is sent to participate on the special emphasis panel. The number of nominees selected will depend on the number of applications received in response to the RFA. Self-nominees who are not selected for this panel/RFA will have the option of having their data retained for future possible engagement opportunities.

Candidates invited to serve on the panel will receive further review relevant instructions and training that is virtual in a group setting from the Scientific Review Officer. In serving in this capacity, they are

full-voting members of the scientific review panel and are expected to follow all the usual guidelines and rules of reviews that scientific reviewers follow.

### **To Apply**

Interested individuals should complete this form: <https://forms.office.com/g/csn5j3SWjU> and send an email providing a resume for their self-nomination. In addition to confirmation of eligibility, applications include:

- Resume in Microsoft Word format mailed to [review4ninds@nih.gov](mailto:review4ninds@nih.gov)
- Contact information (full name, telephone, and email address)
- Requested accommodations
- Reason for interest in public reviewer position
- Brief description of any relevant experience; for example, experience with the disease, experience seeking out or participating in clinical research, or experience interacting with the broader ALS community.
  - Involvement in a clinical trial that is testing a therapy proposed in an application to this FOA will constitute a conflict of interest for this review.

Please send any questions to [review4ninds@nih.gov](mailto:review4ninds@nih.gov). **Only complete [application forms](#) which are paired with an emailed resume, received by 5:30pm EDT on March 23, will be considered.**

### **Scientific Review at NIH and the Role of Public Reviewers**

The NIH dual peer review system is mandated by statute and federal regulations and is based on two sequential levels of review for each application. NIH policy is intended to promote a peer review process whereby grant applications submitted to the NIH are evaluated on the basis of a process that strives to be fair, equitable, timely, and free of bias.

Conflict of interest assessment is made by review staff using NIH-wide COI policies for guidance on a case-by-case basis for funding opportunities like NS-23-012. Due to the timing of the self-nomination period and funding opportunity application deadline, staff are unable to confirm any COI until after the self-nomination period ends. We encourage all interested parties to provide as much detail as possible relating to involvement and/or interactions (ex. advisory, consultancy, participatory) with regard to ALS research efforts.

The first level of review is carried out by a Scientific Review Group (also referred to as study sections or special emphasis panels) composed primarily of non-federal scientists who have expertise in relevant scientific disciplines and current research areas. The selected public reviewer will participate on the Scientific Review Group. **Scientific Review Group rosters are made publicly available in advance of the review meeting.**

The second level of review is performed by Institute and Center (IC) National Advisory Councils or Boards. These Federal Advisory Councils are composed of both scientific and public representatives chosen for their expertise, interest, or activity in matters related to health and disease. More information about the NINDS Advisory Council can be found at <https://www.ninds.nih.gov/about-ninds/who-we-are/national-advisory-neurological-disorders-and-stroke-nandsc-council>.

Only applications that are recommended for approval by both the SRG and the Advisory Council may be recommended for funding. Final funding decisions are made by the IC Directors.

**NINDS relies on the collective opinion of the initial Scientific Review Group members to identify the strongest of the applications whose scientific merit they are charged with evaluating. However, the decision whether to ultimately fund the study (or not) is not a responsibility of the review panel.**

Members of the lay public are included as reviewers of research grant applications on some review panels at NIH. The role of public reviewers is to bring critical perspectives from individuals and family members who have been directly affected by the disease or disorder (in this case, ALS) to the first level of review and to enhance the capability of the review panel to evaluate the “real world” relevance and practicality of each research application. Even though many of the scientific experts have knowledge in these areas, further emphasis on this perspective will help identify the most meritorious applications. In preparation for the review meeting, reviewers will receive applications about four-five weeks prior to the meeting. Reviewers are asked to read the applications and provide critiques, according to specific review criteria for the type of application. Reviewers typically spend several hours reviewing each application and writing critiques.

Critiques from public reviewers focus on the strengths and weaknesses of the application’s public health significance; on issues related to compliance/protocol adherence; on the feasibility of plans for recruitment, retention, and follow-up of subjects; on outreach efforts to special and historically disadvantaged populations; and on issues pertaining to the protection of research participants. Written critiques provided by scientific and public reviewers, with minimal editing, are included in the summary statement (the report released to applicants as the official record of their review).

At review meetings, reviewers selected under this announcement would join the discussion of applications with scientific reviewers and vote on the merit of each application discussed, representing their opinion/perspective alongside other review panel members also assigned to review the application. As the public representative in the peer review process, it is very important to focus on the collective perspective and needs of people affected by ALS during discussions of grant applications, rather than voicing personal or political agendas or engaging in advocacy.

Please send any questions to [review4ninds@nih.gov](mailto:review4ninds@nih.gov). **Only complete application forms which are paired with an emailed resume, received by 5:30pm EDT on March 23, will be considered.**

On behalf of NINDS Scientific Review, thank you for your consideration!

**Samantha White, Ph.D.**