

Committee on ALS: Accelerating Treatments and Improving Quality of Life

Meeting #2: May 18, 2023: Public Session Agenda

Hybrid Meeting: 2101 Constitution Avenue NW, Washington, DC 20418 or live [webcast](#)

Purpose

- Hold *open session* to receive information and engage in discussion with ALS nonprofit leaders about the tools they need to be more effective and impactful in their work.

THURSDAY, MAY 18, 2023 (9:30AM – 12:00PM EST)

OPEN SESSION

9:30–9:40

Welcome and Plans for the Public Session

ALAN I. LESHNER, *Committee Chair*
Chief Executive Officer, Emeritus
American Association for the Advancement of Science

9:40–11:00

What Tools Do ALS Nonprofits Need to be More Effective and Impactful?

The committee invites ALS and related nonprofit organization leaders and advocates to share ideas and suggestions for tools their organization needs to be more impactful and effective in the battle against ALS.

Each speaker is asked to keep remarks to no more than **5 minutes** and **provide ideas and suggestions for tools the ALS nonprofit sector needs to be more impactful and effective in the battle against ALS**.

Separately, the committee welcomes written feedback on the broader, desired recommendations to improve ALS care, quality of life, and therapeutic development in ALS from the perspective of the various ALS nonprofits. Written feedback for the committee can be sent to REnglish@nas.edu.

Remote participants

- Dan Doctoroff, Target ALS
- Sunny Brous, Her ALS Story
- Juliet Pierce, Paralyzed Veterans of America
- Indu Navar, Everything ALS
- Penny Dacks, Association for Frontotemporal Degeneration
- Jean Swidler, Genetic ALS/FTD: End the Legacy
- Blair Casey, Team Gleason
- Jinsy Andrews and James Berry, Northeast ALS (NEALS) Consortium
- Benzi Kluger, International Neuropalliative Care Society

10:20–10:30 Break

In-person participants

- Neil Thakur, ALS Association
- Cathy Collet, More Than Our Stories
- Sonya Elling, I AM ALS
- Paul Melmeyer, Muscular Dystrophy Association

11:15–12:00 Discussion with Committee

ADJOURN OPEN SESSION