

Committee on ALS: Accelerating Treatments and Improving Quality of Life

August 23, 2023: ALS Lived Experiences
Public Workshop Session Agenda

[CLICK HERE TO JOIN](#)

Purpose

- To hear from persons living with ALS and caregivers of persons living with ALS about their experiences to inform study recommendations.

OPEN SESSION

12:00—12:15 Welcome and Introduction to the Workshop

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

12:15—1:00 Panel 1: Understanding Living With ALS

This panel will discuss the experience of living with ALS, the tools and resources that panelists use to support their lives, and the challenges they face.

SARAH LUNSFORD, *Moderator*

Panelists:

DESI KESSLER, Person Living with ALS
PAUL SIEFERT, Person Living with ALS
ASIA JAMI, Person Living with ALS
JIM AND SYLVIA CLINGMAN, Person Living with ALS and Caregiver

1:00—1:45 Panel 2: The Cost of Care

This panel will discuss the costs of ALS care both in terms of financial costs and the emotional and mental health costs for individuals living with ALS and their families as they navigate a care system that often falls short of delivering the tools and resources needed.

SARAH LUNSFORD, *Moderator*

Panelists:

RON FARETRA, Person Living with ALS
KRISTIN RANKIN, Person Living with ALS

JULIAN RODRIGUEZ, Person Living with ALS

JEAN SWIDLER, Pre-Symptomatic Genetic Carrier and Caregiver

1:45–2:00 **Break**

2:00–2:45 **Panel 3: Exploring the Caregiver Experience**

This panel will discuss the different experiences of individuals who care or have cared for people living with ALS. How do caregivers find support and what would they tell someone who was newly diagnosed with ALS about how to live with the disease?

SARAH LUNSFORD, *Moderator*

Panelists:

KATRINA BYRD, Caregiver

VANESSA JACKSON, Caregiver

SIOBHAN PANDYA, Caregiver

ASHLEY LEE, Caregiver

2:45–3:00 **Closing Remarks**

ALAN I. LESHNER, *Committee Chair*

Chief Executive Officer, Emeritus

American Association for the Advancement of Science

END WEBINAR