The ALS Association is recruiting people with ALS and their caregivers for the ALS Focus survey program to capture their needs, preferences and experiences as they meet the challenges of ALS.

FEBRUARY, 2020 TOPIC: UNDERSTANDING INSURANCE NEEDS AND FINANCIAL BURDEN

Information from this survey will help us fight for access to care and financial security for people with ALS and their families.

Bringing the perspectives of people with ALS and their caregivers to the forefront of research, care, and advocacy.

WHAT IS ALS FOCUS?
ALS Focus is a survey program that captures the experiences and perspectives of people with ALS and their caregivers, putting the preferences of people affected by ALS at the center of ALS decision-making.

JOIN US - YOUR VOICE MAKES AN IMPACT
Participate in research in addition to clinical trials.
See your survey responses compared to the rest of the ALS community.

The survey data we collect is:
• Open and free to the entire ALS community
• Protected – All data and findings are de-identified using a unique code called a global unique identifier (GUID)
• Combined with other ALS research studies that use a GUID, such as the National ALS Registry and clinical trials, to broaden the impact of your participation
• Actionable! Data will be used to inform decisions and strengthen programs and policies around:
  ✓ Drug development
  ✓ Clinical trial design
  ✓ Regulatory review
  ✓ Drug payment and reimbursement
  ✓ Clinical care
  ✓ Home health, and more

WHO CAN PARTICIPATE?
• People living with ALS
• Current or past caregivers of people with ALS

*Participants must be at least 18 years old and reside in the United States. Survey instructions and questions are presented in English.

HOW LONG WILL IT TAKE?
Once registered, each secure online survey can be completed in approximately 15-25 minutes.

WHERE?
Access the survey at alsa.org/ALSFocus or use the QR code on this page.

For more information, please contact ALSFocus@alsa-national.org