WHAT IS ALS FOCUS?
ALS Focus is a patient and caregiver-led survey program that asks people impacted by ALS about their needs and burdens. The goal is to learn about individual experiences throughout the disease journey so that the entire ALS community can benefit.

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

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.

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 als.org/ALSFocus or use the QR code on this page.

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