



# 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 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      ✓ Drug payment and reimbursement
  - ✓ Clinical trial design    ✓ Clinical care
  - ✓ Regulatory review      ✓ Home health, and more

**Every step of the survey development process is informed and reviewed by a committee of people with ALS and caregivers.**

## WHO CAN PARTICIPATE?

- People living with ALS
- Current or past caregivers of people with ALS. Spring 2021 survey is for current and past caregivers only.

*\*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?

Registering for Focus and completing the surveys will take approximately 15-25 minutes.

## WHERE?

Access the survey at [als.org/als-focus](https://als.org/als-focus) or use the QR code on this page.

**SPRING 2021 TOPIC: CAREGIVER NEEDS:**  
Past and current caregivers, please share your experiences with us.

**JOIN US — YOUR VOICE MAKES AN IMPACT**  
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.  
Participate in research in addition to clinical trials. Know how your experiences and opinions compare to the rest of the ALS community.

**ALS ASSOCIATION** For more information, please contact [ALSFocus@alsa-national.org](mailto:ALSFocus@alsa-national.org)

