

## 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 unique survey platform led by people with ALS. The goal is to understand the needs, preferences, and experiences of a broad and diverse population of people living with ALS and their caregivers. ALS Focus includes a survey portal that generates new surveys periodically throughout the year to inform and influence decisions that affect our community.
- ALS Focus is a cross-sector collaboration to place the preferences of people with ALS and their caregivers at the center of treatment and policy development, through survey-based research.
- Findings from ALS Focus surveys are open and freely available to the entire ALS community and inform clinical trials design, impact policies and regulatory decision making, payment and reimbursement decisions, patient and caregiver care, and more. Participant identities will not be shared.

### HOW CAN FOCUS HELP ACCELERATE DRUG DEVELOPMENT AND IMPROVE CARE FOR PEOPLE WITH ALS?

ALS Focus surveys collect data and deliver critical information to research, regulatory, and insurance authorities, providing new insights into the experiences, views, and preferences of those living with ALS and their caregivers. ALS Focus surveys a broad range of people with ALS and current and past caregivers across disease progression and around the U.S., improving ALS drug development, clinical trial design, regulatory decisions, payment and reimbursement models, clinical care, home health services, and more.

### WHAT KIND OF INFORMATION IS COLLECTED?

After the registration process, ALS Focus collects

demographic information such as age and gender. A section on health is also included for participants to periodically update their health status. The subsequent surveys collect feedback and insights into the experiences, opinions, preferences, and health outcomes from those living with ALS and their caregivers.

### WHAT ARE THE GOALS OF THE ALS FOCUS PROGRAM?

**Scientific data are highly useful when justifying how to build policies and programs. In ALS Focus, we collect data to:**

- Determine, in a scientifically sound manner, what is most important to people with ALS and caregivers across the spectrum of disease and disease progression.
- Develop and validate tool(s) to measure what is most important to people with ALS.
- Inform policy and regulatory decision making.
- Inform a benefit/risk study and additional preference studies.
- Inform payment and reimbursement decisions.

### HOW WILL SURVEY DATA BE USED?

The surveys inform decisions and strengthen policies and programs around:

- Clinical trial design
- Care services
- Home health practices
- Clinical endpoints and scales
- Regulatory actions and decision-making
- Value-based reimbursement models for ALS therapies

All findings and de-identified data will be shared openly with the entire ALS community for free.

## HOW WILL PARTICIPANT PRIVACY BE PROTECTED?

Participants must first register for an account on the portal by providing their email address and setting a password. Participants (people with ALS and current and past caregivers) will be asked to provide their name, date of birth, and place of birth to generate a Neurological Global Unique Identifier (NeuroGUID). This study refers to a NeuroSTAmP™, which is a NeuroGUID substitute, and serves to de-identify participant responses to all Focus surveys. The personal information that participants enter when generating their NeuroGUID is NOT stored.

## HOW DOES ALS FOCUS DIFFER FROM THE CDC'S NATIONAL ALS REGISTRY?

Data from the National ALS Registry looks for disease pattern changes and seeks to identify whether there are common risk factors among individuals with ALS. Information from the Registry is used to estimate the number of new cases of ALS diagnosed each year and to better understand who gets ALS and what environmental factors affect the disease. In contrast, ALS Focus is a platform for people with ALS and caregivers to communicate their needs, preferences, and experiences as they meet the challenges of ALS throughout the disease journey. Data collected will be used to inform change and strengthen ALS programs and policies.

The CDC is a partner of ALS Focus. People who were assigned a Neurological Global Unique Identifier (NeuroGUID) when they filled out the Registry are eligible to have their Registry data

linked to their ALS Focus data on a de-identified basis. Any researchers who want to use the linked data must have permission from the CDC and the ALS Association.

## WHO CAN PARTICIPATE?

Anyone with ALS, and anyone who is a current or past caregiver of a person with ALS is invited to participate. A proxy is allowed to take the survey on a patient's behalf. The survey program is in English.

## HOW LONG DOES THE SURVEY TAKE TO COMPLETE?

Once registered on the Focus platform, each secure online survey can be completed in approximately 5-15 minutes.

## WHO IS RESPONSIBLE FOR THE ADMINISTRATION OF THE ALS FOCUS SURVEY PROGRAM?

ALS Focus is administered by The ALS Association with support, guidance and oversight from the ALS Focus Steering Committee, which includes co-chairs of the Patient and Caregiver Advisory Committee (PCAC), the Food and Drug Administration (FDA), industry sponsors Apellis, Biogen, Ionis Pharmaceuticals, Cytokinetics, and Biohaven Pharmaceuticals, Revalesio, academic experts, and our partners at Neurological Clinical Research Institute at Massachusetts General Hospital (that houses the Focus survey). The director of the ALS Focus survey program is Sarah Parvanta, Ph.D.

**For more information on als focus, visit <https://www.als.org/als-focus>**

**To sign up, visit <https://www.neuroserver.org/als-focus/Home/login>**

**For a quick start guide on how to register, [click here](#)**

**For questions, please contact [alsfocus@alsa-national.org](mailto:alsfocus@alsa-national.org)**

