**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 views and preferences of people affected by ALS at the center of treatment and policy development. ALS Focus will expand on and develop new data from people with ALS and caregivers about the symptoms, burden, and everyday impact the disease has on people’s lives.

When you sign up for the ALS Focus survey program and complete the quarterly surveys, you are helping to **shape ALS public policy, inform clinical trial design, and strengthen care and service programs for people impacted by ALS. FOR MORE INFORMATION AND TO SIGN UP, VISIT: WWW.ALSA.ORG/ALSFOCUS.**

**WHY PARTICIPATE?**
Your data is actionable!
- Inform recommendations to federal regulators and policy makers in government agencies such as the FDA and CMS, as well as members of Congress
- Help determine what is most important to quality of life for people with ALS and caregivers to help inform payment and reimbursement decisions
- Take part in ALS research in addition to clinical trials
- Inform the drug development and review process, including clinical trial design
- Learn how your experiences with ALS compare to those of others in the community
- Strengthen clinical care and home health practices
- Provide open and free data for global ALS research

**HOW DOES ALS FOCUS HELP TO ACCELERATE DRUG DEVELOPMENT AND IMPROVE CARE FOR PEOPLE WITH ALS?**
ALS Focus surveys collect data that deliver critical information to research, regulatory, and public and private insurers. The data provides new insights into experiences, views, preferences, and health outcomes of those living with ALS and their caregivers. Currently, there is limited information available in existing literature and, where it is available, it’s drawn from a small population. ALS Focus surveys a broad range of people with ALS and caregivers across disease progression and around the U.S. This ultimately improves ALS drug development, clinical trial design, regulatory decisions, drug payment and reimbursement models, clinical care, home health services, and more.
WHO CAN PARTICIPATE?
Anyone with ALS, or 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. All participants must be 18 years of age or older and live in the United States. The survey is in English.

HOW LONG DOES THE SURVEY TAKE TO COMPLETE?
We recognize that your time is valuable and aim to keep surveys short, and less than 15-25 minutes, once registered. However, there may be surveys which will take a little longer. We will do our best to keep these to a minimum. You will receive an email notification when a new survey opens. Each year, at least four new surveys will be released which will cover a variety of topics.

WILL MY INFORMATION REMAIN PRIVATE?
The information you share with ALS Focus is protected by the highest research and privacy standards. Any identifiable information about you as an individual will remain confidential.

WHAT KIND OF INFORMATION IS COLLECTED?
During the registration process, ALS Focus collects basic demographic information such as age and gender. The subsequent surveys collect feedback and insights into the experiences, views, preferences, and health outcomes sought by those living with ALS and their caregivers. The survey data collected 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 some clinical trials, to broaden the impact of your participation and create a robust data set.

WILL I HAVE ACCESS TO THE SURVEY RESULTS?
After the survey is closed, you can log in to the survey portal and view the results and see how your answers compared to other participants in the community.

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 Biogen, Genentech, and Biohaven Pharmaceuticals, academic experts, and our partners at Neurological Clinical Research Institute at Massachusetts General Hospital (that houses the Focus survey platform). The director of the ALS Focus Survey Program is Sarah Parvanta, Ph.D.