

ALS Focus Consent Form

ALS Focus is an online survey platform for people with ALS and caregivers of people with ALS. You will have the option to take surveys about your experiences related to ALS. Participation in ALS Focus takes place online. Surveys are written in English. If you agree to participate, you will be asked to register by answering questions about your ALS status, name, date of birth, place of birth, and sex at birth, which will take approximately 15 minutes to complete. You will also be asked to complete or update a demographics survey, which will take 5 to 10 minutes to complete. You will then be able to complete surveys on a range of topics that explore your perspectives and experiences with the disease. Each survey will take 5 to 10 minutes to complete.

Your participation in any ALS Focus survey is voluntary. If you decide to take part in this study, you may stop participating in surveys at any time. You may email ALSFocus@als.org and request to have your email address removed from the ALS Focus contact list. After removing your email address from the contact list, you will no longer receive ALS Focus notifications or surveys. Any data that was collected from you in the course of this study will remain a part of the survey records and will not be removed.

You will not receive any direct benefits from participating in this study, but your data will contribute to ALS research. If any of the questions make you feel uncomfortable, you may skip those questions or leave the survey. If you face physical difficulty completing the questions, you are permitted to have someone to enter responses on your behalf.

If you decide to participate in research activities offered by the ALS Focus survey platform, information that you provide, such as demographics, disease and family history, your disease progression, medications that you take, possible side effects, and other responses to survey questions will be stored in a secure Qualtrics database. The ALS Association partners with Qualtrics, which provides an online platform to conduct ALS Focus surveys. Your data will be de-identified before analysis.

The email address that you provide for ALS Focus is stored in the secure Qualtrics database and a secure database at The ALS Association. Only approved ALS Focus research staff will have access to your email address and will not use your email address for any purpose outside of ALS Focus.

ALS Focus data collected before April 2022 continue to be stored in a secure research database at the Massachusetts General Hospital's (MGH) Neurological Clinical Research Institute (NCRI) hosted by Partners Enterprise Research Infrastructure and Services (PERIS) server farm.

Neurological Global Unique Identifier (NeuroGUID):

As part of your participation in the ALS Focus survey program, a Neurological Global Unique Identifier (NeuroGUID) surrogate called a NeuroSTAmP will be assigned to you or the person for whom you are responding. The NeuroSTAmP is a unique code of letters and numbers. The NeuroSTAmP is generated using the participant's name, date of birth, place of birth, and sex as shown on the participant's birth certificate. This personal information is encrypted and sent to a secure server at Massachusetts General Hospital's Neurological Clinical Research Institute (NCRI) where the NeuroSTAmP is generated. The personal information is then automatically

deleted from the Qualtrics database. The personal information is not stored by Qualtrics or the NCRI server.

ALS Focus NeuroSTAMPs and survey responses will only be shared as de-identified. De-identified means that your personal information, such as your name or date of birth, will not be attached to your NeuroSTAMP or survey responses. NeuroSTAMPs may be used to connect your ALS Focus survey responses to other studies you participate in, such as clinical research studies, studies of medical records, or other survey platforms. Combining data from multiple studies will increase the likelihood of meaningful analysis and improve our understanding of ALS and the perspectives and experiences of people with ALS. While it may be possible for a researcher in another study that you took part in to identify you if the other study used the same global unique identifier, the usage of the NeuroSTAMP technology minimizes such possibility, as NeuroSTAMPs are uniquely generated for each participant on per study basis.

ALS Focus data will be publicly available for sharing for any research purpose. Your data will be de-identified before sharing and analysis.

This study has been approved by the Western Institutional Review Board (1-800-562-4789). If you have questions about this study, please contact Dr. Sarah Parvanta (ALSFocus@als.org) at The ALS Association, 1300 Wilson Blvd., Suite 600, Arlington, VA, 22209.