Bringing the perspectives of people with ALS and their caregivers to the forefront of research, care and advocacy.

INSTRUCTIONS ON REGISTERING AND COMPLETING SURVEYS

Here is a step-by-step guide on how to register for ALS Focus and complete the surveys. You will need to register for a new account and add yourself as a member on your account.

DIRECTIONS: REGISTER FOR A NEW ACCOUNT

- Step 1: Go to www.alsfocus.org
- Step 2: On the Sign In screen, click on “New User? Sign up new account” which can be found underneath the “Login” button.
- Step 3: On the Sign up new account screen, enter your email address, enter a name of your choosing for your account, and then enter a password of your choosing. Make sure to follow the password rules the bottom of this screen. After entering this information click CREATE NEW ACCOUNT (the green button at the bottom of the screen).
- Step 4: Check your email for a message from ALSFocus@partners.org. In that message, click the link that says, “Click here”. This will take you to a screen saying, “E-mail is confirmed”. Click the LOGIN button on this confirmation screen.
- Step 5: On the login screen that appears, enter your email address and your selected password (from Step 3). You are now logged into your new ALS Focus account.

Each ALS Focus account can have multiple members. For example, a person with ALS and his/her caregiver can each have their own memberships on the same account. This way, a family only needs to keep track of one account, rather than multiple accounts.

Next each person on their ALS Focus account must add themselves as a member.

DIRECTIONS: ADD YOURSELF AS A MEMBER ON YOUR ACCOUNT

- Step 1: After logging into your account, you will see a Welcome screen. Click Add New Member.
- Step 2: On the Add a Member screen, add yourself as a member by entering a name or nickname of your choosing. This name will be your member name on your account. Every time you log into your ALS Focus account, you will click on this member name.
ALS FOCUS INSTRUCTIONS

- Step 3: On the Add a Member screen, answer the questions and indicate whether you are a caregiver or a person with ALS. Click SAVE MEMBER.
- Step 4: On the Members screen that says, “Who do you want to enter information for?”, click Continue on the square that lists your member name.
- Step 5: On the Consent screen, review the consent form and answer the questions at the bottom of the consent form.
- Step 6: On the NeuroSTAmP* screen, enter the required information to create your unique identifier. Make sure the information you enter is valid. This information will not be stored. Click GENERATE NEUROSTAMP. You will not be shown the unique identifier that is created for you.
- Now you’re ready to complete the ALS Focus surveys listed on the Home screen!

DIRECTIONS: COMPLETING THE SURVEYS

- Step 1: On the Home screen, click About Me to answer questions on demographics and health status.
- Step 2: After completing the About Me survey, go back to the Home screen and click the Survey on Insurance Needs and Financial Burden.
- Note, you must complete the About Me survey before the Survey on Insurance Needs and Financial Burden.

*A NeuroSTAmP is a type of global unique identifier (GUID). Each participant in ALS Focus needs a unique identifier.

- A person with ALS who wants to participate should enter his/her own information to create a unique identifier.
- A current or past caregiver who wants to participate should enter his/her own information to create a unique identifier.
- A proxy who will is filling out surveys on behalf of a person with ALS should enter information for the person with ALS to create a unique identifier for the person with ALS.

Your NeuroSTAmP will help to connect data across research studies if you participate in more than one study. Combining data from multiple studies will increase the chance for meaningful analysis and help improve our understanding of the disease and the perspectives of people with ALS, current caregivers, and past caregivers.