

## Persons with ALS (PALS) Quick Start Guide

Thank you for your interest in joining the National ALS Registry. This document will take you through the registration process for persons with ALS (PALS) and show you how to access National ALS Registry Surveys. Surveys are only available to registered PALS.

### **How to get to the National ALS Registry**

Open your web browser and go to <http://www.cdc.gov/als>.

### **How to Join the National ALS Registry**

**Step One:** Click the "Join The Registry" link located in the "Join the National ALS Registry and Take ALS Risk Factor Surveys" section on the "National ALS Registry" homepage.

**Step Two:** Click the "Join ALS Registry" button located at the bottom of the "Persons with ALS (PALS) Account" box.

**Step Three:** Read the "Account Notification Consent Form". If you agree, click the "I Agree" button located at the bottom of the "Account Notification" box.

**Step Four:** Answer the "PALS Validation Questions". Click the "Next" button to proceed to the next question. Answering these questions verifies your eligibility to participate in the registry.

**Step Five:** Read the "National ALS Registry Consent Form". Clicking on the "I Agree" button means that you consent to participating in the registry.

**Step Six:** Read the "ALS Research Notification Consent Form". Clicking on the "I Agree" check box means that you consent to receive ALS Research Notifications. If you do not want to receive ALS Research Notifications, leave the "I Agree" check box blank. Click the "Next" button to continue the registration process.

**Step Seven:** Fill in all of the required fields located on the "Create Persons with ALS (PALS) Account" page. All required fields are marked with a red asterisk (\*). Remember your user name and password. You will need these to log into the registry to take new risk factor surveys and to retrieve or update your account information. Click the "Submit" button located at the bottom of the "Create Persons with ALS (PALS) Account" box. When you have successfully joined the registry, you will see a green box that says "Registration Completed"

## Appendix C8 – PALS Quick Start Guide

### **How to take an Available Survey on the National ALS Registry**

Remember, in order to complete a survey, you must first register as a person with ALS.

**Step One:** Click the "Surveys" link located at the bottom of the surveys "Registration Completed" box on the "PALS Account Confirmation" page.

**Step Two:** To view instructions for the surveys, click the "General Instructions" link located above the "Surveys" box on the "Risk Factor Surveys Homepage". These instructions can also be printed for future reference on how to complete the surveys.

**Step Three:** To take a survey, click a Survey Number or Survey Name located in the Survey column on the "Risk Factor Surveys" page. You can take the first six surveys only one time. You can complete the seventh, "Quality of Life," survey every six months. Taking this survey each six months will help measure your disease progression. You will be notified by email when your Quality of Life and future surveys become available.

### **How to access your Account Settings**

**Step One:** Click the "My Account" link located at the bottom of the surveys "Registration Completed" box on the "PALS Account Confirmation" page.

**Step Two:** On the "Persons with ALS (PALS) Account" page, you can take risk factor surveys, update your account information, change your password, or contact the System Administrator. All of these features can be accessed by click the appropriate link on the "Persons with ALS (PALS) Account" page.

### **How to access Risk Factor Surveys and your Registry Account at a later time or date**

**Step One:** Type your user name into the "Username" field located in the "Already Registered? Log in Here to Access Your Account and Take ALS Risk Factor Surveys" section. This is same user name you created when you first joined the registry.

**Step Two:** Type your password into the "Password" field located in the "Already Registered? Log in Here to Access Your Account and Take ALS Risk Factor Surveys" section. This is the same password you created when you first joined the registry.

**Step Three:** Click the "Login" button located at the bottom of the "Already Registered? Log in Here to Access Your Account and Take ALS Risk Factor Surveys" section box.

Should you need help registering, please call us at 877-442-9719 Monday-Friday between 9am-6pm ET. You may also send us your request via e-mail to [ALSSystemAdmin@cdc.gov](mailto:ALSSystemAdmin@cdc.gov).