

Form Approved
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Promotion of the National Amyotrophic Lateral Sclerosis (ALS) Registry

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What will be covered today

- The National ALS Registry (Registry)
- Importance of Registry self-enrollment
- Why we need your help
- Preparing you to talk to your ALS patients about the Registry
 - What you can do
 - Self-enrollment demonstration
- Resources for neurologists
- How to reach us

The National ALS Registry

- ALS is a non-reportable disease.
- Uncertainty of the incidence, prevalence, and etiology of the disease in the US. 
- Public Law No: 110-303 established the Registry.
- The Agency for Toxic Substances and Disease Registry (ATSDR) maintains the Registry.
- It is the only population-based Registry for the entire US.

Registry goals

- The goal of the Registry is to gather information that can be used to:
 - Estimate the number of new cases of ALS each year,
 - Estimate the number of people who have ALS at a specific point in time,
 - Better understand who gets ALS and what factors affect the disease,
 - Examine the connection between ALS and other MNDs that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS, and
 - Improve care for people with ALS.

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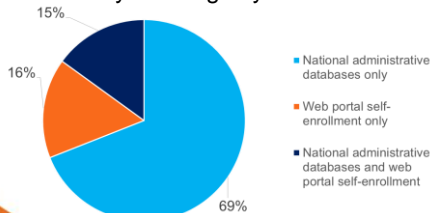
Registry data: A Two-Pronged Approach

- Data from national administrative databases
 - Medicare
 - Medicaid
 - Veterans Health Administration
 - Veterans Benefits Administration
- Secure patient self-enrollment web portal
 - A US citizen or legal resident
 - 18 years of age or older

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Registry enrollment by source

- From October 19, 2010 through December 31, 2011, a total of 12,187 people with ALS were identified by the Registry*



* Mehta P, Antao V, Kaye W, et al. Prevalence of amyotrophic lateral sclerosis—United States, 2010-2011. MMWR 2014;63(No. SS-7):1-13.

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Importance of self-enrollment

- By self-enrolling, people living with ALS can:
 - Ensure they are counted in the Registry.
 - The algorithm applied to the administrative databases misses about 20% of cases.
 - Complete risk factor surveys.
 - Sign up to receive notifications for other research project for which they may be eligible to participate.

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Why we need your help

- Neurologists typically diagnose/treat people with ALS
- Approximately 5,000 new ALS cases are diagnosed every year.
- Self-enrollment is lower than expected, especially among non-whites and older individuals.
- Neurologists have an opportunity to educate these individuals about the Registry.
- Your commitment and participation are needed to make the Registry a success.

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What can you do?

- We hope you will talk to your ALS patients about the Registry
- To guide your discussion you may follow the 5A framework
 - Ask, advise, assess, assist, arrange

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What can you do?

- Ask your ALS patient if they have enrolled in the Registry

If Yes:

- Explain the importance of completing the risk factor surveys

If No:

- Advise to enroll
- Assess if interested in enrolling
- Assist with enrollment
- Arrange to talk about enrollment at next appointment

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Advise to enroll

- Explain the benefits of enrolling
- Answer questions
- Provide a brochure
- Ask patients to visit the Registry website: www.cdc.gov/ALS
- Provide the ATSDR Registry phone number (800-232-4636)

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Advise to complete the risk factor surveys

- Ask patients to complete the 17 surveys
 - Questions will ask patients about who they are, where they lived or worked, family history of ALS, hobbies and other activities in which they take part, and how they are coping with ALS.
 - Average 5 minutes to complete (per survey)
 - Range from 1-24 questions
 - Do not need to be completed all at once

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Assess if interested in enrolling

- Answer questions about the Registry
- Ask if patient tried to enroll or will enroll

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Assist with enrollment

- Provide a copy of the step-by-step infographic
- Ask patients to visit the Registry website: www.cdc.gov/ALS
- Tell them about the six minute tutorial video
- Ask patients if they have a personal email address
- Offer to help them enroll
- Suggest other support networks

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Arrange to talk about enrollment at next appointment

- Tell patient you will remind them about the and surveys
- Tip: Flag medical chart for future discussion

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Self-enrollment steps

1. Log on to www.cdc.gov/ALS
2. Click "JOIN THE REGISTRY"
3. Click "Join ALS Registry" on bottom left in the box "Persons with ALS (PALS) Account"
4. Account notification screen: Read and click "I agree"
5. Answer screening questions
6. National ALS Registry consent form. Click "I agree"
7. Consent to receive emails for clinical research
8. Complete account registration
9. Create username, password, and security questions
10. Registration complete

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1. Log on to: www.cdc.gov/als



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2. Click on: "JOIN THE REGISTRY"



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6. National ALS Registry consent form. Click "I agree"

800-232-4636
TTY (888) 232-6348
Monday-Friday
8am-5pm
Closed Holidays
Contact CDC/NIH

Risks
The major risk of taking part is someone getting your information. To keep this from happening, we will limit who can see your information. We will also have computer security that keeps your information safe.

Benefits
There are no direct benefits to you. In the future, your information could help others with ALS.

Confidentiality
Your information will be kept private to the extent allowed by law. Only authorized individuals will have access to your information. Your information will be stored in a secure location with limited access. Any information that is published about people in the registry will not identify you.

Results
The website where you registered will have reports about what we learn from people who take part in the National ALS Registry and surveys.

Voluntary
Taking part is up to you. You do not have to take part and you can stop taking part at any time. You will not lose any benefits to which you are entitled if you do not take part or choose to quit.

If you have any questions about the surveys, you can contact Dr. Paul Mehika toll free at 1-877-442-5719. If you have any questions about your rights as a research participant, you can contact the Human Research Protection Office at 1-800-554-6814.

By clicking on I AGREE, you are agreeing to take part.

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7. Consent to receive emails for clinical research

ATSDR

Join the Registry
Learn

Consent Form - ALS Research Notification

Research is an important part of the National ALS Registry. Not all research is done by ATSDR. Sometimes other ALS researchers would like to contact people in the National ALS Registry to ask them to take part in Research Notification. If you want to receive emails from ATSDR about ALS research notifications, please check the "I Agree" box below.

We will not give the researchers your name or contact information. If you want to be part of a project, you will have to contact the researcher listed in the email.

I Agree

Contact Us:
Agency for Toxic Substances and Disease Registry
4770 Buford Road NE
Atlanta, GA 30341

800-232-4636
TTY (888) 232-6348
Monday-Friday
8am-5pm
Closed Holidays
Contact CDC/NIH

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8. Complete account registration

Create Accounts with ALS (ALS) Access

Title: Select Registry Number:

Organization: Select Email Registry Number:

First Name: Last Name:

Address: City:

State: Zip:

Country:

Phone: Fax:

State of Birth:

Personal and Registry Email Consent
I am interested in being the contact address regarding my National ALS Registry. The information in this field goes through our information and is not shared.

I Agree

Security Question
This information is used for account creation. It can contain letters, numbers, and special characters.

Question:

Security Question
This information is used for account creation. It can contain letters, numbers, and special characters.

Question:

Answer:

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Resources for Neurologists

- Website - www.cdc.gov/ALS
 - Free CME module
 - <http://www.atsdr.cdc.gov/emes/ALS/>
 - Registry materials available to download and order
 - <https://www.cdc.gov/als/ALSOrderRegistryMaterials.aspx>
- Contact us

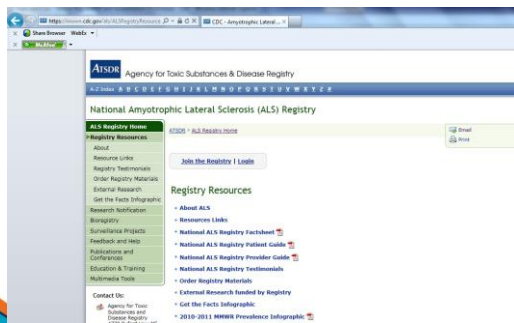
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The CME module provides

- Free continuing education contact hours (1.5 CME, 1.5 CNE, 1.5 CHES, 0.2 CEU)
- A clinical overview on ALS
- Current clinical practice recommendations for diagnosis, treatment, and management of patients with ALS, including communication strategies
- Information on the importance of standard diagnostic coding procedures for diagnosis of ALS patients in clinical practice
- Information on the National ALS Registry and the importance of ALS patient self enrollment in the Registry

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Available Registry materials



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How to contact our team

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Thank you for your time.



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