

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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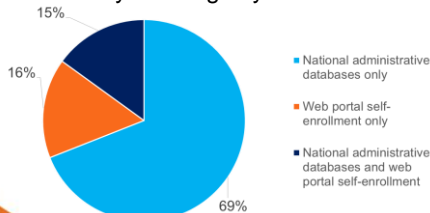
Registry data: A Two-Pronged Approach

- 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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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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