National ALS Registry:
A Multi-Faceted Research Platform

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Disclosures

- None
- The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention/the Agency for Toxic Substances and Disease Registry and should not be construed to represent any agency determination or policy.

U.S. ALS Registry Act

- **Enacted as Public Law 110-373 (October, 2008)**
- **Directed CDC/ATSDR to create a population-based U.S. registry**
- **National ALS Registry launched in October 2010**
- **Registry purposes (as specified by the Act)**
  - Describe incidence and prevalence of ALS
  - Describe the demographics of ALS patients
  - Examine risk factors for the disease
- **ALS is non-notifiable to CDC in the United States**

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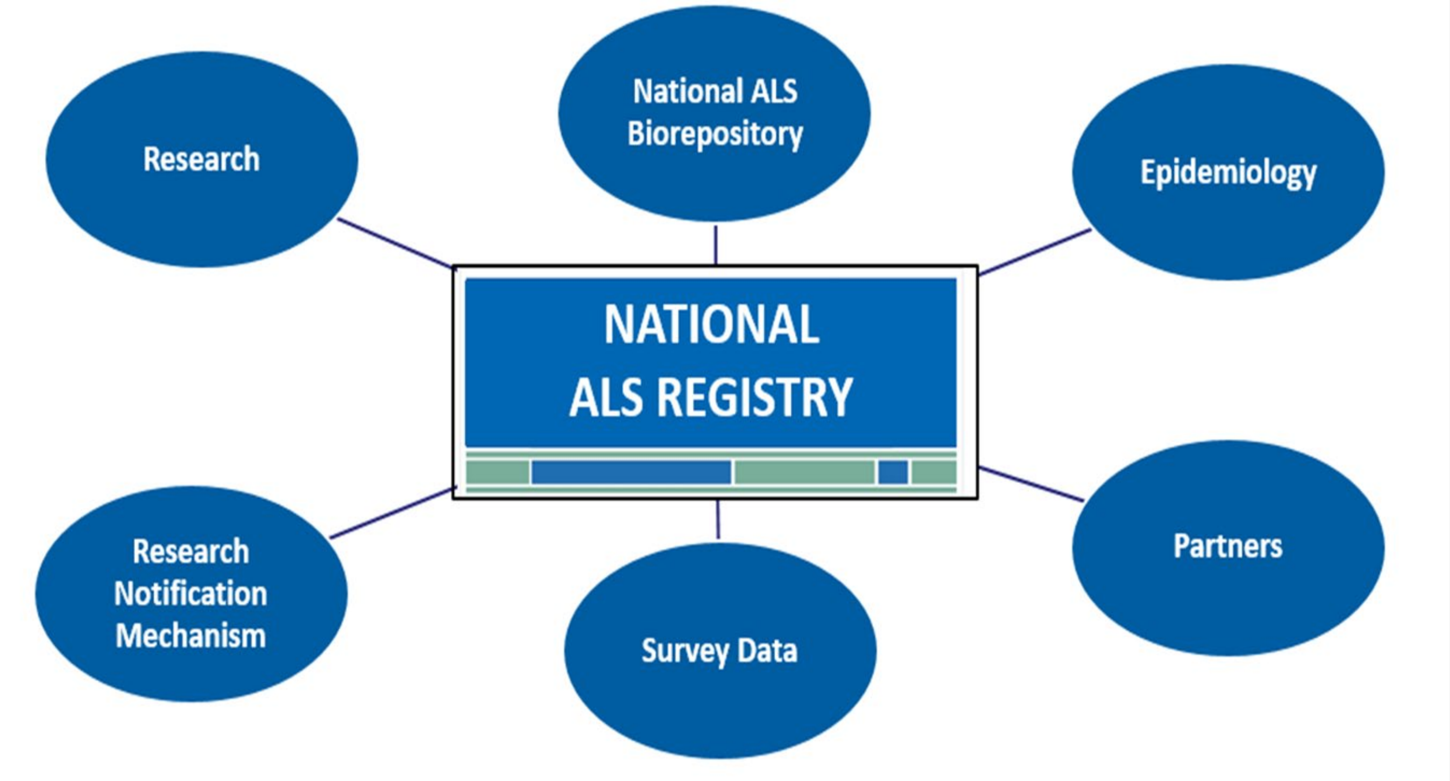

ALS Program Recommendations

- **NIH has tasked NASEM to accelerate ALS treatments and research.**
- **NASEM has asked the CDC/ATSDR's National ALS Registry along with other agencies (e.g., DOD CDRMP) to provide 2-3 recommendations to improve the success and pace of ALS research.**
- **The ALS program synthesized the following recommendations.**

NASEM = National Academies of Science, Engineering, and Medicine

NIH = National Institutes of Health

DOD CDRMP = Department of Defense Congressionally Directed Medical Research Program

Recommendations

1. Utilize existing research platforms (e.g., National ALS Registry) to facilitate and augment the recruitment of persons with ALS into clinical trials and studies as well as better understand the national epidemiological trends. This should reduce costs for industry and increase enrollment and participation for persons with ALS.

Recommendations

2. The identification of possible risk factors and etiologies for ALS is key to reducing the public health burden and making this disease livable by 2030. Without knowing and identifying the possible cause(s) of ALS, it will be difficult to reduce the incidence, prevalence, and mortality of this disease which in turn could lead to a faster diagnosis.

Recommendations

3. Coordination with other federal agencies on funding opportunity announcements, possibly joint proposals, and the sharing of resources can lead to research advancements and demonstrate to the public that these collaborative initiatives are important and beneficial. Currently, there is confusion by the public on how federal agencies advance ALS research and what each organization is mandated to do by Congress.

Comments/Questions

www.cdc.gov/als

The National ALS Registry: Get The Facts

The National Amyotrophic Lateral Sclerosis (ALS) Registry enables persons with ALS to fight back and help defeat ALS (Lou Gehrig's Disease). By signing up, being counted, and answering brief questions about your disease, you can help researchers find answers to critical questions.

Learn more at www.cdc.gov/als or (800) 232-4636

Who can sign-up?
Anyone with ALS

What do I need?

- A computer with an internet connection
- An email address

No computer? Don't worry! A family member, caregiver, or friend with a computer can help you. You can also contact:

What if I need help?
Caregivers and others can help you in person or even over the phone

What kind of information is collected?

- Basic demographics (e.g., age, sex, height, weight)
- Military history
- Physical activity
- Family history

Will my information be private?

- YES! Only approved registry scientists can see it, NOT employers or insurers
- You CANNOT be looked up in the registry by name

Do I need to update my information?
YES! Every six months – you'll get an email reminder

YOU JOINING =

More information for research

A better understanding of ALS

The chance to help create a better future for persons with ALS

For more information, contact NCEH/ATSDR
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.atsdr.cdc.gov www.cdc.gov
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