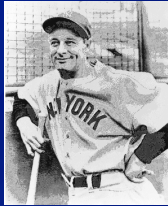



**Implementation of the National Amyotrophic Lateral Sclerosis (ALS) Registry**



D. Kevin Horton, DrPH, MSPH, CPH

Advances in Epidemiologic Methods, Research and Surveillance  
November 9, 2010

Division of Health Studies  
Surveillance and Registries Branch



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**Presenter Disclosures**

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**The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:**

“No relationships to disclose”

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**Agency for Toxic Substances and Disease Registry (ATSDR)**

- A federal agency of the U.S. Department of Health and Human Services
- Sister agency of the CDC, responsible for environmental health issues (i.e., toxic substances)
- “Serve the public through responsive public health actions to promote healthy and safe environments and prevent harmful exposures”:
  - Health assessments/consultations
  - Health surveillance and registries
  - Health studies
  - Emergency response
  - Applied research

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**Purpose of a Registry**

- **Collect and analyze information about registrants, including illnesses, risk factors, and exposures**
  - Exposure Registries
  - Disease Registries
- **Provide information to registrants about health services and other services available to them**

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**Need for a National ALS Registry**

- **ALS (Lou Gehrig's disease) is a progressive, fatal, neurodegenerative disease caused by the degeneration of motor neurons.**
  - Approximately 80% of cases die within 2-5 yrs of diagnosis
- **Lack of reliable incidence, prevalence estimates by geographic area**
- **National estimates rely heavily on nonspecific mortality data**

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**ALS Pilot Projects**

- **Conducted 4 pilots during 2006 - 2009:**
  - MN, GA, SC, and an HMO consortium
- **Purpose** – to determine the feasibility of conducting a national ALS registry using large national databases
- **Outcome** – developed algorithm for sufficiently identifying ALS patients from large national databases (predictive value positive– 85%)

The Past
The Present
The Future

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The Past  
The Present  
The Future

### Preliminary Data

□ **National Databases (2001 – 2005)**

	Medicare		Medicaid		VA		Total	
	N	%	N	%	N	%	N	%
<b>ALS</b>	<b>15,460</b>	<b>24%</b>	<b>3,456</b>	<b>23%</b>	<b>1,839</b>	<b>16%</b>	<b>16,226</b>	
Potential	18,932	29%	3,447	23%	3,023	26%	22,096	
Not ALS	31,245	48%	8,050	54%	6,556	57%	44,338	
<b>Total</b>	<b>65,637</b>		<b>14,953</b>		<b>11,418</b>		<b>82,660</b>	

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The Past  
The Present  
The Future

### ALS Registry Act

□ **Enacted as Public Law 110-373 (October, 2008)**

□ **Directs ATSDR to establish/maintain the Registry**

□ **Purposes**

- Describe incidence and prevalence of ALS
- Describe the demographics of ALS patients
- Examine risk factors for the disease

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The Past  
The Present  
The Future

### The National ALS Registry

□ **2 pronged approach for capturing ALS cases**

- **National databases\***: apply algorithm to Veteran's Benefits Administration, Veteran's Health Administration, Medicare, and Medicaid databases
- **Web portal**: to capture patients not in the national databases. Portal will also contain risk factor modules

□ **Web portal launched on 10/19/10 (≈ 1500 cases to date)**

\* Represents approximately 90,000,000 Americans

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The Past
The Present
<b>The Future</b>

### Upcoming Plans

- ❑ **Funding state/metro based surveillance projects**
  - To test the completeness of the National ALS Registry
  - 3 state Health Departments: NJ, TX, & FL
  - 4-6 metro-based Health Departments selected by year's end
  - Data collection: 2009-2011
  - State/metro data available to ATSDR in 2012
- ❑ **Exploring the feasibility of linking DNA and brain banking**
- ❑ **Sharing Registry data with researchers**

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### Comments/Questions?


[www.cdc.gov/als](http://www.cdc.gov/als)

### Visit us at Booth 1966

For more information please contact Agency for Toxic Substances and Disease Registry  
4770 Buford Hwy, NE, Chamblee, GA 30341  
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348  
E-mail: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov) Web: [www.atsdr.cdc.gov](http://www.atsdr.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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