Northern New England Amyotrophic Lateral Sclerosis (ALS) Surveillance Registry
REGISTRY INFORMATION SHEET v. 5/1/13

We are requesting your permission to report information on your health status to the Northern New England ALS Surveillance Registry. The purpose of this registry is to learn more about how medical, environmental and inherited factors affect the development of ALS. One of our goals is to find ways of preventing diseases such as ALS from occurring or progressing.

Your participation is voluntary. Your decision whether or not to participate in this Registry, or a decision to withdraw, will have no effect on the quality of your medical care or your relationship with your neurologist.

The information we will collect for this Registry will include demographic information such as your name, address, gender, date and place of birth. We will also collect information about your diagnosis of ALS, your tobacco use history, and whether or not a family member has ALS. This information will be used for research purposes only and will be kept strictly confidential.

Efforts will be made to protect the names of the participants in this Registry. Reports will be stored in locked cabinets. Data will be kept on a secure computer server or in encrypted files. Results of data analysis will be published in group form only and information will not be traceable to any single source or individual. Individually identifiable data elements will be destroyed after the data are no longer needed.

Your health information will be maintained indefinitely for future research studies. Your permission to gather this health information will expire in 2 years; however you may change your mind at any time before then. If you do, simply let us know in writing, and we will stop collecting health information about you from that point forward. A decision to withdraw from this registry will have no affect on your medical care and involve no loss of benefits to which you are otherwise entitled. Information we collect before you withdraw from the Registry will continue to be used by researchers.

Questions about this project may be directed to:

Dr. Elijah Stommel  
Department of Neurology  
One Medical Center Drive  
Lebanon, NH 03756-0001  
Phone: (603) 650-8589  
E-mail: Elijah.W.Stommel@hitchcock.org

If you have questions regarding research, you may contact the Office of the Committee for the Protection of Human Subjects at Dartmouth College during normal business hours: (603) 646-3053.

If you agree to be part of this Registry, no action is needed by you. If you would prefer not to be in this Registry, please check the box below.

☐ I DO NOT wish to participate in the Northern New England ALS Surveillance Registry.
Northern New England ALS Registry Case Reporting Form

Name of person completing form: __________________________ Date Completed: __/__/___

Clinic/hospital: __________________________ City: __________ State ______

Phone: (____) __________ Email: _______________________________

This form is part of a regional registry initiative to define the population of individuals diagnosed with ALS in Northern New England. The information that is being collected will enable future projects to learn more about risk factors for ALS. This form should only be completed for individuals meeting the diagnosis of ALS based on the El Escorial Criteria* for diagnosing ALS, who are residents of New Hampshire or Vermont at the time of diagnosis.

The presence of ALS requires each of the following:
1. Lower Motor Neuron (LMN) signs by clinical, electrophysiological, or neuropathological examination, in 1 or more of 4 regions (bulbar, cervical, thoracic, and lumbosacral). Signs include weakness, muscle atrophy and fasciculations.
2. Upper Motor Neuron signs (by clinical examination) in 1 or more of the 4 regions. Signs of upper motor neuron involvement include increased muscle tone or spasticity, spastic gait, hyperreflexia.
3. Progression of signs within a region or to other regions
4. Electrophysiological evidence or neuroimaging to exclude other disease processes that might explain the LMN and/or UMN degeneration.

Definite ALS: UMN & LMN signs in the bulbar region and 2 other spinal regions or the presence of UMN and LMN signs in 3 spinal regions.
Probable ALS: UMN & LMN signs in ≥2 regions. While the regions may be different, some UMN signs must be rostral (above) the LMN signs.
Possible ALS: UMN and LMN signs are in only 1 region or UMN signs alone are present in ≥2 regions or LMN signs are rostral to UMN signs. Monomeric ALS (one limb), progressive bulbar palsy, and progressive primary lateral sclerosis without spinal LMN signs constitute special cases which may develop LMN or UMN signs to meet the criteria for probable ALS with time or be subsequently confirmed at autopsy by neuropathology.


Check one: ☐ Individual opted out of the Registry. If yes, please provide the following: Age: ______ Gender: ______
☐ Individual has been verbally informed, has been given an information sheet, and has agreed to participate.

Subject Information
1. Last Name: __________________________ First Name: __________________________ Middle Initial: ______
2. Residential address at time of diagnosis:

<table>
<thead>
<tr>
<th>Number</th>
<th>Street</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
</tr>
</thead>
</table>

Demographic Information
3. Date of Birth: __/__/___ (mm/dd/yyyy)
4. Gender: ☐ Male ☐ Female
5. Race/Ethnicity (as reported by subject, check all that apply):
   - ☐ Asian
   - ☐ Black/African American
   - ☐ Hispanic or Latino
   - ☐ Other: _______________
6. Place of Birth: __________________________
   City: __________ State: ______ Country: ______

Medical History
7. Does the patient have an immediate family member (parent, sibling, child) who has/had ALS?
   - ☐ Yes ☐ No ☐ Don’t know
8. Does the patient have dementia diagnosed by a neurologist?
   - ☐ Yes, FTD (Frontotemporal dementia)
   - ☐ Yes, other type (Alzheimer’s, Lewy Body, other/unspecified)
   - ☐ No ☐ Don’t know
9. Does the patient have a history of tobacco use? (defined as smoking >100 cigarettes in a lifetime)
   - Cox: Current user (smoking within 1 year of diagnosis)
   - ☐ Yes: Former user (quit >1 year prior to diagnosis)
   - ☐ Non-user ☐ Don’t know

Diagnosis Information
10. El Escorial Criteria as determined by neurologist:
    - ☐ Definite ☐ Possible
    - ☐ Probable ☐ Not Classifiable
11. Date of Diagnosis: __/__/___ (mm/dd/yyyy)
12. Estimated year of symptom onset: __ __ __ (yyyy)
13. Was EMG/NCS performed?
    - ☐ Yes ☐ Not Performed
14. Provider Making the Report
    - ☐ ALS specialist
    - ☐ Neurologist (general or other subspecialty)
    - ☐ Internal Medicine/General Practice
    - ☐ Other: ________________________
15. Has the patient been referred to an ALS Center?
    - ☐ DHMC ☐ UVM/FAHC ☐ Yale ☐ MGH ☐ UMass
    - ☐ Other: ________________________ ☐ No ☐ Don’t know
16. Has the patient had genetic testing for ALS?
    - ☐ Yes ☐ No ☐ Don’t know
17. Has the patient taken Riluzole, currently or previously?
    - ☐ Yes ☐ No ☐ Don’t know

Please mail or fax the completed form to
Dr. Elijah Stommel, DHMC Neurology, One Medical Center Drive, Lebanon, NH 03756-0001.
Phone: (603) 650-5000 Fax: (603) 650-6233
For questions regarding this form, please call or contact Elijah.W.Stommel@hitchcock.org.