

# Neurological Clinical Research Institute @ MGH

# Human Postmortem Tissue Core Public Search

Manual of Operations v. 1.0

May 2016

This publically available search interface enables researches around the world to query the Target ALS Multicenter Human Postmortem Tissue Core for available fixed and frozen tissue samples of specific anatomical regions from subjects meeting selectable clinical and demographic criteria.

A main reason for this search is to help researchers use our <u>Tissue Request Form</u> to make requests for samples that are reasonable given what is available for use.

Please note that frozen tissue availability generally implies availability of ~75-200 mg individual samples (varies depending on anatomical region) and fixed tissues are generally provided as unstained "Plus-coated" glass slides. See the Tissue Request Form for further details

Click here to access the Public Search

## **Table of Contents**

HOW TO SEARCH POSTMORTEM TISSUES	
WHAT RESULTS WILL MY SELECTIONS PRODUCE?	
- SUBJECT CHARACTERISTICS:	
- TISSUE REGIONS:	
START SEARCHING FOR SAMPLES:	
SEARCH EXAMPLESSEARCH FIELDS	
Subjects Characteristics	
TISSUE REGIONS	6
BUTTONS	
ERROR MESSAGES	

#### HOW TO SEARCH POSTMORTEM TISSUES

#### What results will my selections produce?

The search will not return a list of specific cases, or case-specific details. Rather, it will generate a count of the number of cases with samples meeting the criteria specified that are currently available across all sites in our multicenter Core.

The following are generic "rules of engagement" for performing searches:

#### Subject Characteristics:

- The user MUST select at least one Subject type (ALS or Non-Neurologic Controls) to produce search results. If both ALS and Non-Neurologic Controls are selected, the search will return two separate results – one for each subject type.
- "Ghosted" subject characteristics become selectable when the parent category is selected. For example, ALS must be selected to be able to select fALS, and fALS must be selected to be able to select SOD-1.
- Any checkbox selected on the <u>same</u> <u>horizontal row</u> produces results for all subjects combined in those categories (so-called "union" or "OR"). For example, if both **SOD1** and **C9orf72** are selected, the results will contain any subjects who possess either of these mutations. If checkboxes on <u>different</u> horizontal rows are selected, for example, **Male** and Bulbar, the results will contain only patients that are both male AND had bulbar onset.
  - Note that **Both** under "Site of Symptom Onset" implies that there was simultaneous onset in both the extremities and bulbar regions.
- If a specific class of subject characteristic is not specified, the results will contain cases for which that data does not exist in the database. For example, selecting both Bulbar and Extremities will include subjects who had symptom onset in either the bulbar region OR their extremities, while leaving the Site of Symptom Onset fields blank will <u>also include cases for which site of onset is not known (or not specified).</u>
- For the following characteristics the user MUST specify **From** AND **To** values:
  - Age at Symptom
  - Disease Duration
  - Age at Death

#### - Tissue Regions:

• If no tissue regions are selected, the results will include all cases meeting the specified

subject characteristics, regardless of tissue inventory.

- If both **Paraffin Sections** and **Fresh Frozen Tissue** are selected, the results will only include cases for which both frozen and paraffin tissue is available for the selected regions.
- If specific tissue regions are selected, the results will include all cases for which *all* of the selected regions are available which meet the selected subject characteristics.
- Note that the tissue regions are hierarchical for example, selecting **Cortical regions** will return cases with *any* cortical region available, or alternatively specific cortical regions can be selected. If more than one specific region is selected, the results will only include cases for which both regions are available.

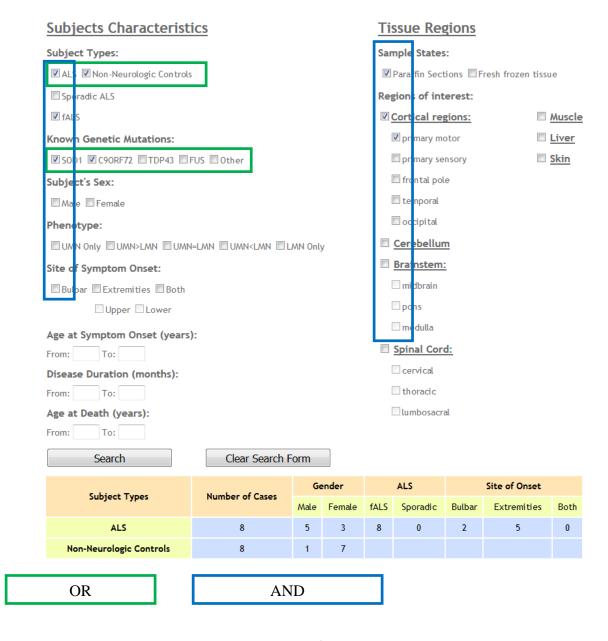
Note that other tissue regions and subject characteristics (including neuropathological features) can be requested – see the "Tissue Request Form" for details.

### **Start searching for samples:**

- 1. Select at least one subject type
- 2. Select other necessary subject characteristics (Optional)
- 3. Select at least one sample state (Optional)
- 4. Select one or more tissue regions (Optional)
- 5. Click Search button
- 6. Click "Clear Search Form" button to reset/clear the form.

#### **SEARCH EXAMPLES**

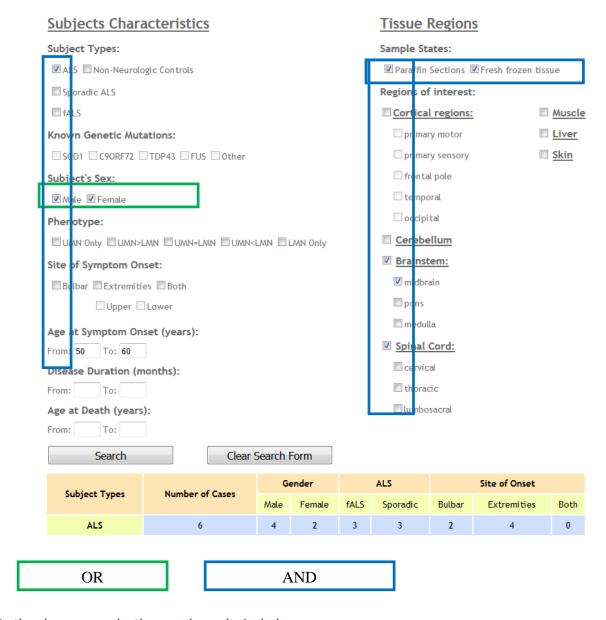
#### Example 1:



In the above example, the search returns two rows of results:

- The number of **ALS** cases with **familial type ALS (fALS)** with **SOD1** OR **C9ORF72** mutations that have **Paraffin sections** of **Primary motor** cortex available.
- The number of **Non-Neurologic Controls** cases that have **Paraffin sections** of **Primary motor** cortex available.

## Example 2:



In the above example, the search results include:

- ALS cases that are either Male OR Female
  - AND Age at Symptom Onset ranges between 50 and 60
  - AND have both *Paraffin sections* AND *Fresh-frozen tissue* samples of both *midbrain* and ANY *Spinal Cord* region(s).

# SEARCH FIELDS

#	Fields	Description			
Subj	Subjects Characteristics				
1	ALS	Amyotrophic Lateral Sclerosis (ALS) patients			
2	Non-Neurologic Controls	Cases that had no known neurologic diseases			
3	Sporadic ALS	Cases with no known ALS disease-causing gene mutations <u>AND</u> less than 2 known relatives with ALS.			
4	fALS (familial ALS)	Cases with 2 or more relatives with ALS <u>OR</u> cases with a known ALS disease-causing mutation.			
5	Known Genetic Mutations	Can specify cases with a known mutation in SOD1, C9ORF72, TDP43, or FUS. Other = Cases with another known ALS disease-causing mutation that is not listed.			
6	Subject's Sex	Male or Female. If neither is selected, it will also include cases for which sex is not specific in the database.			
7	Phenotype	<ul> <li>- UMN Only: Primary Lateral sclerosis (PLS)</li> <li>- UMN &gt; LMN: Upper motor neuron predominant (UMND)</li> <li>- UMN=LMN</li> <li>- UMN</li> <li>- UMN</li> <li>- LMN Only: Progressive muscular atrophy (PMA)</li> </ul>			
8	Site of Symptom Onset	- Bulbar - Extremities – can further specify Upper or Lower - Both : Simultaneous onset in bulbar region AND extremities			
9	Age at Symptom Onset (years)	Age at Symptom Onset is the difference between Date of Symptom Onset and Date of Birth			
10	Disease Duration (months)	Disease duration is the difference between <i>Date of Symptom Onset</i> and <i>Date of Death</i>			
		Only full (completed) months returned from calculations of <i>Disease Duration</i> . For example:  1.3 will be calculated as 1 full month  1.9 will also be calculated as 1 full month			
		Cases for which Age at Symptom Onset is not known will not be included in the results.			
11	Age at Death (years)	Age at Death is the difference between Date of Death and Date of Birth			
Tissu	ue Regions				
12	Sample States	- Paraffin Sections - Fresh-frozen tissue			
13	Regions of interest	List of sample types (nomenclature)			

Buttons		
14	Search	Clicking <b>Search</b> will return the results in a tabular format
15	Clear Search Form	Clicking <i>Clear Search Form</i> will reset the search form

Error Messages			
#	Error	Meaning	
1	Please, select at least one parameter from Subject Characteristics!	The user must select at least <i>Subject Type</i> , otherwise the system will not produce results	
2	Your search did not produce any results!	The system did not find any cases for the selected or entered criteria	