

Extended dataset for the UK MND Collections

An extended dataset has been collected from as many participants as possible but is not a complete dataset.

When requesting fields from the extended dataset, please consider the most important information you require. The priorities of the information will affect the samples available to you (due to the incomplete dataset mentioned above).

Clinical History

- Site of presentation
- Family history of: MND, Parkinson's Disease, Alzheimer's Disease, Frontotemporal dementia, other neurological condition
- Dominant hand
- Inconsistent features: sensory, autonomic, sphincter, Parkinsonian, cognitive

Family Tree Pedigree

- Parents, grandparents, siblings, children and 'other'
- Affected/unaffected, age now, sex, alive (y/n), age at death, year of death, cause of death

Investigations and Results

- Nerve conduction studies: central motor, motor, sensory conduction respectively and conduction block
- EMG: right and left upper limbs, right and left lower limbs and tongue respectively
- Blood: CK, antiganglioside Abs, Kennedy's mutation, SOD1 mutation*
- MRI of brain, cervical, thoracic, lumbosacral spinal cord respectively

All individual investigations above are recorded according to one of the following categories: **Unknown, normal, abnormal, abnormal relevant, abnormal irrelevant, not taken**

Current Medications

- Current medications – drug and notes
- Disease modifying medications – drug, date started and notes

ALSFRS-R

Divided into each of the 12 categories (including the with and without gastrostomy sub-categories) and a total score

Physical Examination History

- Upper motor neurone signs in bulbar, lower limb and upper limb
- Lower motor neurone signs in bulbar, lower limb and upper limb
- Weight in kilos (at time of giving sample)
- %FVC
- %VC

MRC Scores

- Neck flexion and extension respectively
- **Upper limb:** shoulder abduction, elbow flexion, wrist flexion, wrist extension, thumb abduction – each for right and left side respectively
- **Lower limb:** hip flexion, knee flexion, knee extension, ankle dorsiflexion – each for right and left side respectively

Notes Fields

- Significant past medical history
- Family history
- Nerve conduction notes
- EMG studies
- Blood results
- MRI examinations
- Other significant abnormal investigations
- Physical examination history