

D - Neuro - Huntington's Disease

Please complete the survey below.

Thank you!

1. Gold Standard Diagnosis:

Does the participant have Huntington's Disease (HD)?

- ☐ Yes
☐ No
☐ Not certain

How was this confirmed? Check all that apply

- ☐ Genetic Testing
☐ Consistent clinical presentation with genetically confirmed family history

[DEPRECATED]

Does the participant have Huntington's disease (HD) confirmed by genetic testing?

- ☐ Yes
☐ No
☐ Not certain

Is the CAG repeat length known?

- ☐ Yes
☐ No

What is the CAG repeat length?

[DEPRECATED]

Does the participant have Huntington's disease confirmed by consistent clinical presentation with genetically confirmed family history?

- ☐ Yes
☐ No
☐ Not certain

2. Disease Subtype

Disease Subtype

- ☐ Pediatric Onset
☐ Juvenile Onset
☐ Adult Onset
☐ Late Onset
☐ Unknown

3. Disease Severity

Motor Exam

UHDRS total motor score

UHDRS speech training

UHDRS total chorea score

DCL (Diagnostic Confidence Level)

HD Total Functional Capacity Rating Scale

Occupation ☐ 0 = unable
☐ 1 = marginal work only
☐ 2 = reduced capacity for usual job
☐ 3 = normal

Finances: ☐ 0 = unable
☐ 1 = major assistance
☐ 2 = slight assistance
☐ 3 = normal

Domestic chores: ☐ 0 = unable
☐ 1 = impaired
☐ 2 = normal

Activities of daily living: ☐ 0 = total care
☐ 1 = gross tasks only
☐ 2 = minimal impairment
☐ 3 = normal

Care level: ☐ 0 = full time skilled nursing
☐ 1 = home or chronic care
☐ 2 = home

Total: _____

4. Treatment obtained

Has the participant undergone any treatment for Huntington's disease? ☐ Yes
☐ No
☐ Not certain

Please select the type of treatment: ☐ Medications
☐ Prior or current SLP therapy

Please select all that apply and provide further details if available ☐ Neuroleptic
☐ VMAT2 inhibitor
☐ Antidepressant
☐ Benzodiazepine

Neuroleptic selected. Please specify _____

VMAT2 inhibitor selected. Please specify _____

Antidepressant selected. Please specify _____

Prior or current SLP therapy selected. Please select all that apply: ☐ Prior
☐ Current