



MDS-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS)

Introduction to the European Reference Network for Rare Neurological Diseases (ERN-RND):

ERN-RND is a European Reference Network established and approved by the European Union. ERN-RND is a healthcare infrastructure which focuses on rare neurological diseases (RND). The three main pillars of ERN-RND are (i) network of experts and expertise centres, (ii) generation, pooling and dissemination of RND knowledge, and (iii) implementation of e-health to allow the expertise to travel instead of patients and families.

ERN-RND unites 32 of Europe's leading expert centres in 13 Member States and includes highly active patient organizations. Centres are located in Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Italy, Lithuania, Netherlands, Poland, Slovenia, Spain and the UK.

The following disease groups are covered by ERN-RND:

- Ataxias and Hereditary Spastic Paraplegias
- Atypical Parkinsonism and genetic PD
- Dystonia, Paroxysmal Disorder and Neurodegeneration with Brain Ion Accumulation
- Frontotemporal Dementia
- Huntingtons' Disease and other Chorea
- Leukodystrophies

Specific information about the network, the expert centres and the diseases covered can be found at the networks web site www.ern-rnd.eu.

Recommendation for clinical use:

The European Reference Network for Rare Neurological Diseases recommends the use of the MDS-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS) as best clinical practice for the assessment and rating of genetic Parkinson's disease.



Disclaimer:

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METHODOLOGY

The endorsement process has been performed by the Disease group for Atypical Parkinson of ERN-RND.

Disease group for Atypical Parkinsonism and genetic PD:

Disease group coordinators:

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Disease group members:

Healthcare professionals:

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Patient representatives:

John McFarlane²⁰

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Endorsement process:

- Mapping of used disease scales by disease group – June 2017– May 2018
- Proposal for endorsement of rating scale by ERN-RND disease group coordinators – 15/05/2018
- Discussion in ERN-RND disease group during annual meeting – 08/06/2018
- Consent on endorsement of disease scale during ERN-RND annual meeting 2018 – 08/06/2018
- Consent on endorsement by whole disease group – 25/09/2018



Reference to disease scale:

<https://www.movementdisorders.org/MDS/MDS-Rating-Scales/MDS-Unified-Parkinsons-Disease-Rating-Scale-MDS-UPDRS.htm>

