



Unified Multiple System Atrophy Rating Scale (UMSARS)

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 Unified Multiple System Atrophy Rating Scale (UMSARS) as best clinical practice for the assessment and rating of Multiple System Atrophy.



Disclaimer:

Clinical practice guidelines, practice advisories, systematic reviews and other guidance published, endorsed or affirmed by ERN-RND are assessments of current scientific and clinical information provided as an educational service. The information (1) should not be considered inclusive of all proper treatments, methods of care, or as a statement of the standard of care; (2) is not continually updated and may not reflect the most recent evidence (new information may emerge between the time information is developed and when it is published or read); (3) addresses only the question(s) specifically identified; (4) does not mandate any particular course of medical care; and (5) is not intended to substitute for the independent professional judgement of the treating provider, as the information does account for individual variation among patients. In all cases, the selected course of action should be considered by the treating provider in the context of treating the individual patient. Use of the information is voluntary. ERN-RND provided this information on an “as is” basis, and makes no warranty, expressed or implied, regarding the information. ERN-RND specifically disclaims any warranties of merchantability or fitness for a particular use or purpose. ERN-RND assumes no responsibility for any injury or damage to persons or property arising out of or related to any use of this information or for any errors or omissions.

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:

Thomas Gasser¹, Wassilios Meissner²

Disease group members:

Healthcare professionals:

Alberto Albanese³; Norbert Brüggemann⁴; Yaroslau Compta⁵; Malgorzata Dec-Cwiek⁶; Maria Teresa Dotti⁷; Antonio Elia⁸; Antonio Federico⁷; Dusan Flisar⁹; Barbara Garavaglia⁸; Zoltan Grosz¹⁰; Christine Klein⁴; Jiri Klempir¹¹; Thomas Klockgether¹²; Thomas Klopstock¹³; Maja Kojovic⁹; Norbert Kovacs¹⁴; Bernhard Landwehrmeier¹⁵; Johannes Levin¹³; Gerrit Machetanz¹; Maria Jose Marti⁵; Anne Pavy-Le Traon¹⁶; Bart Post¹⁷; Evžen Růžička¹⁸; Francesc Valldeoriola⁵; Wim Vandenberghe¹⁹



Patient representatives:

John McFarlane²⁰

¹ Universitätsklinikum Tübingen, Germany; ² CHU de Bordeaux, France; ³ IRCCS Clinical Institute Humanitas – Rozzano, Italy; ⁴ Universitätsklinikum Schleswig-Holstein, Germany; ⁵ Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain; ⁶ University Hospital in Krakow, Poland; ⁷ AOU Siena, Italy; ⁸ Foundation IRCCS neurological institute Carlo Besta – Milan, Italy; ⁹ University Medical Centre Ljubljana, Slovenia; ¹⁰ Semmelweis University, Hungary; ¹¹ General University Hospital in Prague, Czech Republic; ¹² Universitätsklinikum Bonn, Germany; ¹³ Klinikum der Universität München, Germany; ¹⁴ University of Pécs, Hungary; ¹⁵ Universitätsklinikum Ulm, Germany; ¹⁶ Centre Hospitalier Universitaire de Toulouse, France; ¹⁷ Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, Netherlands; ¹⁸ Motol University Hospital, Czech Republic; ¹⁹ University Hospitals Leuven, Belgium; ²⁰ European Polio Union

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

Wenning Gregor K., et al. Development and validation of the Unified Multiple System Atrophy Rating Scale (UMSARS), Mov Disord. 2004 Dec;19(12):1391-402.

