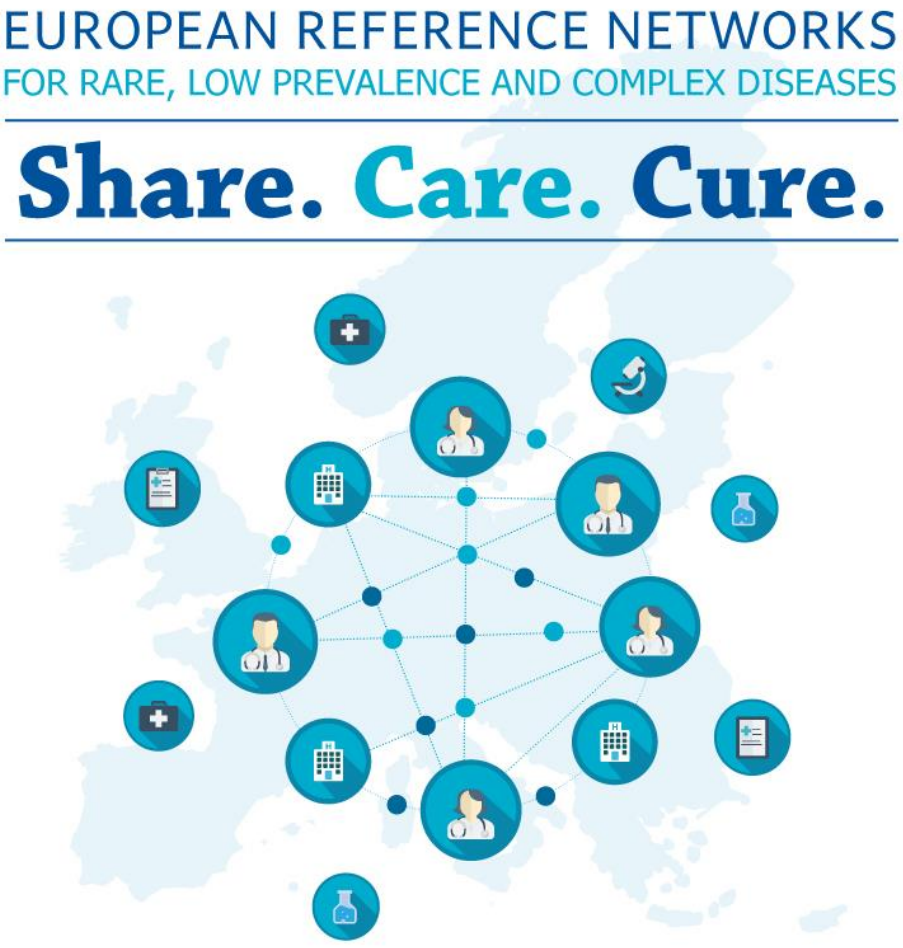
European Reference Networks

European Reference Network for rare or low prevalence complex diseases

Network: Neurological Diseases (ERN-RND)

Coordinator: Universitätsklinikum Tübingen — Deutschland

UNIFIED MULTIPLE SYSTEM ATROPHY RATING SCALE (UMSARS)



Endorsed by ERN-RND: 25/09/2018 (Update: Dec 2024)

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Luxembourg: Publications Office of the European Union, 2019

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 64 of Europe's leading expert centers as well as 4 affiliated partners in 24 member states and includes highly active patient organizations. Centers are located in Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Slovenia, Spain and Sweden.

The following disease groups are covered by ERN-RND:

- Ataxias and Hereditary Spastic Paraplegias
- Atypical Parkinsonism and genetic Parkinson's disease
- Dystonia, Paroxysmal Disorder and Neurodegeneration with Brain Iron Accumulation
- Frontotemporal Dementia
- Huntington's Disease and other Choreas
- Leukodystrophies

Specific information about the network, the expert centers and the covered diseases can be found on the network's website ***www.ern-rnd.eu***.

Recommendation for clinical use:
The European Reference Network for Rare Neurological Diseases recommends the use of 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 not 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 Parkinsonism and Genetic PD of ERN-RND.

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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
- Endorsement of updated document: 11/10/2024

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Co-funded by the European Union