

EHDN PHYSIOTHERAPY PRACTICE GUIDELINES FOR HUNTINGTON'S DISEASE CLINICAL CARE

<https://ehdn.org/clinical-guidelines/>

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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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 centres as well as 4 affiliated partners in 24 Member States and includes highly active patient organizations. Centres are located in Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, The 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 Disorders and Neurodegeneration with Brain Ion Accumulation
- Frontotemporal Dementia
- Huntington's Disease and other Chorea
- Leukodystrophies

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

Affirmation of value:

The European Reference Network for Rare Neurological Diseases has affirmed the value of these guidelines.

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METHODS

The endorsement process has been performed by the Working Group for Neurorehabilitation of ERN-RND.

Consent on endorsement was given by the entire Working Group on: 12 July 2023

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REFERENCES

1. [EHDN Physiotherapy Working Group; Physiotherapy Clinical Guidelines; 2013; https://ehdn.org/wp-content/uploads/2016/08/English_version.pdf](https://ehdn.org/wp-content/uploads/2016/08/English_version.pdf)
2. [EHDN Physiotherapy Working Group; HD Physiotherapy 2020 guidelines: Summary for HD families; 2020; https://ehdn.org/wp-content/uploads/2021/01/HD-Clinical-Guidelines_Lay-Summary_FINAL-Europe.pdf](https://ehdn.org/wp-content/uploads/2021/01/HD-Clinical-Guidelines_Lay-Summary_FINAL-Europe.pdf)
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3. [EHDN Physiotherapy Working Group; HD Physiotherapy 2020 guidelines: Summary for healthcare professionals; 2020; https://ehdn.org/wp-content/uploads/2021/01/HD-Clinical-Guidelines_professional-Summary-FINAL-Europe.pdf](https://ehdn.org/wp-content/uploads/2021/01/HD-Clinical-Guidelines_professional-Summary-FINAL-Europe.pdf)



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