



European
Reference
Network

for rare or low prevalence
complex diseases



Network

Neurological Diseases
(ERN-RND)

Consensus clinical management guideline for pantothenate kinase- associated neurodegeneration (PKAN)

Molecular Genetics and Metabolism 120, 2017, 278-87

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 Parkinson's disease
- 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.

Affirmation of value:

The European Reference Network for Rare Neurological Diseases has affirmed the value of this guideline as best clinical practice for pantothenate kinase-associated neurodegeneration (PKAN).



Disclaimer:

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Reference to original guideline:

[Hogarth P et al. Consensus clinical management guideline for pantothenate kinase-associated neurodegeneration \(PKAN\). Mol Genet Metab. 2017 Mar;120\(3\):278-287.](#)

