



Clinical Rating Scale for Pantothenate Kinase- Associated Neurodegeneration (PKAN)

Movement Disorders, Volume32, Issue11, November 2017,
Pages 1620-1630

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 Parkinsons' 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.

Recommendation for clinical use:

The European Reference Network for Rare Neurological Diseases strongly recommends the use the following scale as Clinical Rating Scale for Pantothenate Kinase-Associated Neurodegeneration (PKAN).



Disclaimer:

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METHODOLOGY

The endorsement of the clinical rating scale for PKAN was done by the Disease group for Dystonia, Paroxysmal Disorder and NBIA of ERN-RND. Scales used in the clinical practice of the disease group members were mapped, and the decision on which scale should be proposed was taken by anonymous majority voting.

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Endorsement process:

- Consent to endorse document by whole disease group – 18.06.2019

Reference:

[Darling A, Tello C, Martí MJ, Garrido C, Aguilera-Albesa S, Tomás Vila M, Gastón I, Madruga M, González Gutiérrez L, Ramos Lizana J, Pujol M, Gavilán Iglesias T, Tustin K, Lin JP, Zorzi G, Nardocci N, Martorell L, Lorenzo Sanz G, Gutiérrez F, García PJ, Vela L, Hernández Lahoz C, Ortigoza Escobar JD, Martí Sánchez L, Moreira F, Coelho M, Correia Guedes L, Castro Caldas A, Ferreira J, Pires P, Costa C, Rego P, Magalhães M, Stamelou M, Cuadras Pallejà D, Rodríguez-Blazquez C, Martínez-Martín P, Lupo V, Stefanis L, Pons R, Espinós C, Temudo T, Pérez Dueñas B. \(2017\) Clinical rating scale for pantothenate kinase-associated neurodegeneration: A pilot study. *Mov Disord.* 32\(11\):1620-1630](#)

