

CLINICAL RATING SCALE FOR LEUKOENCEPHALOPATHIES

GROSS MOTOR FUNCTION CLASSIFICATION IN METACHROMATIC LEUCODYSTROPHY (GMFC-MLD)

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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INTRODUCTION TO THE EUROPEAN REFERENCE NETWORK FOR RARE NEURO 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 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, 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 Chorea
- 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 the GMFC-MLD as best clinical practice for the assessment and rating of Leukoencephalopathies.

Please keep in mind that this scale has been developed for Metachromatic Leukodystrophy (MLD), assessing gross motor function only. In the absence of a specific and general scale for Leukoencephalopathies, ERN-RND nonetheless recommends the use of GMFC-MLD.

DISCLAIMER

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METODOLOGY

The endorsement process has been performed by the Disease group for Leukoencephalopathies of ERN-RND.

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Endorsement process:

- Proposal for endorsement of the rating scale by ERN-RND disease group coordinators: 18th December 2024
- Discussion in ERN-RND disease group on 18th December 2024
- Consent on endorsement by whole disease group – 10th March 2025

LINK TO ORIGINAL PUBLICATION

KEHRER, C., BLUMENSTOCK, G., RAABE, C. and KRÄGELOH-MANN, I. (2011), **Development and reliability of a classification system for gross motor function in children with metachromatic leucodystrophy.** Developmental Medicine & Child Neurology, 53: 156-160. <https://doi.org/10.1111/j.1469-8749.2010.03821.x>

RATING SCALE FOR GROSS MOTOR FUNCTIONS IN MLD: GMFC-MLD

Level 0	Walking without support with quality of performance normal for age
Level 1	Walking without support but with reduced quality of performance, i.e. instability when standing or walking
Level 2	Walking with support. Walking without support not possible (fewer than five steps)
Level 3	Sitting without support and locomotion such as crawling or rolling. Walking with or without support not possible
Level 4	(a) Sitting without support but no locomotion or (b) Sitting without support not possible, but locomotion such as crawling or rolling
Level 5	No locomotion nor sitting Without Support, but head control is possible
Level 6	Loss of any locomotion as well as loss of any head and trunk control



https://ec.europa.eu/health/ern_en



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