

# CLINICAL RATING SCALE FOR LEUKODYSTROPHIES

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

EUROPEAN REFERENCE NETWORKS  
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

**Share. Care. Cure.**



Endorsed by ERN-RND: 10 March 2025

Published by ERN-RND on 12 February 2026

## Disclaimer:

“The European Commission support for the production of this publication does not constitute endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.”

More information on the European Union is available on the Internet (<http://europa.eu>).

Luxembourg: Publications Office of the European Union, 2019

© European Union, 2019

Reproduction is authorised provided the source is acknowledged.

## 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 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, 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](http://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 Leukodystrophies.***

***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 all Leukodystrophies, ERN-RND nonetheless recommends the use of GMFC-MLD.***

## 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.

## METODOLOGY

The endorsement process of the Gross Motor Function Classification in Metachromatic Leukodystrophy has been performed by the Disease Group for Leukodystrophies of ERN-RND.

## Disease group Leukodystrophies:

### Disease group coordinators:

Kleopas Kleopa<sup>8</sup>; Nicole Wolf<sup>1</sup>; Samuel Gröschel<sup>30</sup>

### Disease group members:

#### Healthcare professionals:

Ales Tomek<sup>20</sup>; Andrea Mignarri<sup>4</sup>; Ángel Martín<sup>17</sup>; Anna Ardissona<sup>14</sup>; Anna Fetta<sup>15</sup>; Anneli Kolk<sup>26</sup>; Aoife Mahony<sup>16</sup>; Arina Novasa<sup>21</sup>; Bart Dermaut<sup>29</sup>; Beata Błażejewska-Hyżorek<sup>13</sup>; Caroline Sevin<sup>5</sup>; Caterina Garone<sup>15</sup>; Christa-Caroline Bergner<sup>32</sup>; Daniel Boesch<sup>2</sup>; Dimitri Hemelsoet<sup>29</sup>; Duccio Maria Cordelli<sup>15</sup>; Enrico Bertini<sup>22</sup>; Ettore Salsano<sup>14</sup>; Fran Borovec<sup>28</sup>; Francesco Nicita<sup>22</sup>; Giovanna De Michele<sup>2</sup>; Hanna Küpper<sup>30</sup>; Hans Hartmann<sup>11</sup>; Hendrik Rosewich<sup>30</sup>; Ieva Glazere<sup>21</sup>; Isabella Moroni<sup>14</sup>; Iwona Stępnia<sup>13</sup>; Johanna Uusimaa<sup>10</sup>; Jorgen Erik Nielsen<sup>23</sup>; Karolina Ziora-Jakutowicz<sup>13</sup>; Klára Brožová<sup>27</sup>; Laszlo Szpisjak<sup>25</sup>; Lena Elisabeth Hjermand<sup>23</sup>; Leonardo Ulivi<sup>3</sup>; Luca Solina<sup>15</sup>; Lucia Laugwitz<sup>30</sup>; Ludger Schöls<sup>30</sup>; Mar O'Callaghan<sup>12</sup>; Marc Engelen<sup>1</sup>; Mario Habek<sup>28</sup>; Marjo van der Knaap<sup>1</sup>; Natalja Predkele<sup>21</sup>; Nicola Giannini<sup>3</sup>; Odile Boespflug-Tanguy<sup>5</sup>; Pedro Oliva Nacarino<sup>6</sup>; Peter Balicza<sup>24</sup>; Pierre Kolber<sup>7</sup>; Rachele Danti<sup>14</sup>; Rosa Cortese<sup>4</sup>; Sabine Groenborg<sup>23</sup>; Steffi Dreha-Kulaczewski<sup>11</sup>; Sylvia Boesch<sup>19</sup>; Thomas Klopstock<sup>18</sup>; Tom de Koning<sup>31</sup>; Veronica Di Pisa<sup>15</sup>; Wolfgang Koehler<sup>32</sup>

#### Patient representatives:

Sara Hunt<sup>9</sup>

<sup>1</sup>Amsterdam UMC - Amsterdam University Medical Center, Netherlands; <sup>2</sup>AOU - Federico II University Hospital, Naples, Italy; <sup>3</sup>AOU - University Hospital Pisa, Italy; <sup>4</sup>AOU - University Hospital Siena, Italy; <sup>5</sup>APHP - Reference Centre for Leukodystrophies, Robert-Debré University Hospital, Paris, France; <sup>6</sup>Asturias Central University Hospital, Oviedo, Spain; <sup>7</sup>CHL - Luxembourg Hospital Center, Luxembourg; <sup>8</sup>Cyprus Institute of Neurology and Genetics, Egkomi, Cyprus; <sup>9</sup>ePAG; <sup>10</sup>Finland Consortium: University Hospitals in Oulu, Tampere and Helsinki, Finland; <sup>11</sup>Hannover Medical School, Germany; <sup>12</sup>Hospital Clinic Barcelona and Sant Joan de Déu Hospital, Barcelona, Spain; <sup>13</sup>Institute of Psychiatry and Neurology, Warsaw, Poland; <sup>14</sup>IRCCS - Foundation of the Carlo Besta Neurological Institute, Milan, Italy; <sup>15</sup>IRCCS - Institute of Neurological Sciences of Bologna, Italy; <sup>16</sup>Irish Consortium: Tallaght University Hospital and Children's Health Ireland; <sup>17</sup>La Paz University Hospital, Madrid, Spain; <sup>18</sup>Ludwig Maximilian University Hospital, Munich, Germany; <sup>19</sup>Medical University Innsbruck, Austria; <sup>20</sup>Motol University Hospital, Prague, Czech Republic; <sup>21</sup>Pauls Stradins Clinical University Hospital, Riga, Latvia; <sup>22</sup>Pediatric Hospital Bambino Gesù, Rome, Italy; <sup>23</sup>Rigshospitalet University Hospital Copenhagen, Denmark; <sup>24</sup>Semmelweis University, Budapest, Hungary; <sup>25</sup>Szent-Györgyi Albert Medical Center, Szeged, Hungary; <sup>26</sup>Tartu University Hospital, Estonia; <sup>27</sup>Thomayer University Hospital, Prague, Czech Republic; <sup>28</sup>University Hospital Center Zagreb, Croatia; <sup>29</sup>University Hospital Ghent, Belgium; <sup>30</sup>University Hospital Tübingen, Germany; <sup>31</sup>University Medical Center Groningen, Netherlands; <sup>32</sup>University of Leipzig Medical Center, Germany

## Endorsement process:

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

Source: see reference or <https://doi.org/10.1111/j.1469-8749.2010.03821.x>

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 <b>and</b> locomotion such as crawling or rolling. Walking with or without support not possible
Level 4	(a) Sitting without support but no locomotion <b>or</b> (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



# European Reference Networks

[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)



## European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Neurological Diseases  
(ERN-RND)

 **Coordinator**  
Universitätsklinikum  
Tübingen — Deutschland

[www.ern-rnd.eu](http://www.ern-rnd.eu)

Co-funded by the European Union

