



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Neurological Diseases
(ERN-RND)

Minimal requirements for information given about MRI data in publications

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 MRI data in publications:

The European Reference Network for Rare Neurological Diseases strongly recommends to give at least the following additional information when presenting MRI images in publications.



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 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.

METHODOLOGY

The requirements for additional information to MRI pictures in publications was compiled by the Disease group for Leukodystrophies of ERN-RND.

Disease group for Leukodystrophies:

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Minimal requirements for information to be given with MRI pictures in publications:

Structure	Affected / not affected
Periventricular white matter (par occ / temp / fron)	
Central white matter (par occ / temp / fron)	
Subcortical white matter (par occ / temp / fron)	
Corpus callosum (genu)	
Corpus callosum (body)	
Corpus callosum (splenium)	
Cortex	
Basal ganglia	
Thalamus	
Mesencephalon	
Brain stem	
Cerebellar white matter	
Dentate nucleus	
Cerebellar cortex	
Spinal cord	
Dorsal columns	
lateral corticospinal tracts	
ventral corticospinal tracts	
grey matter	
General	
Supratentorial atrophy: inner CSF spaces	
Supratentorial atrophy: outer CSF spaces	
Cerebellar atrophy: vermis	
Cerebellar atrophy: hemispheres	
Other important findings	



Illustration (minimal requirements)	level
axial t2	centrum semiovale
	Basal ganglia / thalami
	(mesencephalon)
	cerebellar white matter
sag image (T1 or T2)	mid sagittal
ALWAYS provide age at MRI	
<i>additional images depending on pathology</i>	
T1 (with / without contrast)	
FLAIR	
SWI	
DWI (incl ADC)	

Describe white matter findings using standard terminology	predominant where?
	confluent / multifocal
	contrast enhancing?
	cystic/rarefied?
	symmetric / asymmetric ?
	other characteristics (calcifications, microbleeds...)
	signal intensity on T2 and T1

